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Extended Research Article

Intersecting factors of disadvantage and discrimination and their effect on daily life during the coronavirus pandemic: the CICADA-ME mixed-methods study

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Scientific summary

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Introduction

The COVID-19 pandemic exposed and exacerbated multiple pre-existing societal inequities for people from minoritised ethnic groups in the UK and those with poor health or disability. Mortality statistics captured public and government attention. But the ways in which intersecting factors of disadvantage and discrimination affected other aspects of their pandemic experience have been largely ignored. For example, international concern about pandemic-induced mental health issues has sidelined the especially poor pandemic-related mental health of people from some minoritised ethnic groups.

Objectives

Our aim was to address the gaps by contributing and informing evidence-based formal and informal strategies, guidelines, recommendations and interventions for health and social care policy and practice, to mitigate inequities and improve the experiences and social, health and well-being outcomes of minoritised ethnic groups at the intersection with disabling chronic conditions or impairments.

This necessitated in-depth understanding of relevant influences on mental and physical health, coping, access to resources, and informal and formal social and healthcare support from different intersecting combinations of disability and ethnicity. Citizenship status is also critical; many recent refugees and undocumented migrants will have 'no recourse' to support. Though the study centres on these intersections, we necessarily also explore other categories of societal difference (e.g. age, gender) that interact with them under institutional and structural conditions to create specific health outcomes and experiences.

We included comparison with people self-identifying as of White British heritage, with/without disability, and non-disabled people from minoritised ethnic groups to help unpack intersectional patterns.

Our objectives, using an intersectionality lens, were to:

1. explore and compare, by location and time, survey and qualitative data on changing need for social, health and well-being outcomes
2. relate pandemic coping strategies/solutions to objective 1 findings, including what worked well or less well, and touchpoints (where experiences might best be improved)
3. explore formal and informal network issues/affordances in health and social care solutions
4. gain insights from convergence synthesis of our mixed-methods data
5. contextualise and explore transferability of findings
6. co-create with stakeholders identified strategies and interventions, and plans for rapid pathways to impact.

Methods

We used a transformative, convergent parallel mixed-methods design integrating three strands – quantitative, qualitative and a secondary data strand – across three phases over 18 months, to answer the study objectives.

Strands 2 and 3 involved concurrent primary data collection, with repeated measures in three 'waves' over 18 months. This allowed us to explore experiences and attitudes within changing pandemic contexts, relations between these, intersectional identities and health and well-being, and enhanced the ecological validity of our work. Our data synthesis followed a triangulation design; qualitative data were merged and compared with quantitative data.

Strand 1: secondary data analyses

We analysed existing cohort and panel data and undertook a scoping literature review, and fed these into the other strands, though they were not dependent on this.

Strand 2: primary survey and quantitative analysis

We developed a new survey for community-dwelling migrants and UK/Republic of Ireland-born children of migrants, also White British comparators, all with/without disability. In wave 1, we used data from 4326 respondents, of whom 3498 completed wave 2 and 3100 wave 3. Approximately half our sample were of minoritised ethnicity and approximately half had a chronic condition or disability; we intentionally oversampled from these groups for good statistical power and a sound understanding.

Strand 3: primary qualitative methods

Strand 3 aimed for in-depth understanding, with semistructured interviews (n = 271), follow-on co-create workshops with interviewees (n = 104) to explore changes 5 and 10 months later and exchange knowledge, and stakeholder workshops with health professionals, community leaders, charity leads and participants (n = 30) to co-design simple-to-implement solutions to issues. We asked policy-makers, general practitioners (GPs) and community leaders (n = 4) how to put these into immediate practice. The interviews were undertaken by a core academic research team, eight community researchers recruited from UK migrant charities, and partners Bromley-by-Bow Community Centre and Born In Bradford.

From the 271 interviews, a core data set of 218 met our initial criteria of living in England, being significantly impacted by a chronic condition or disability, and being of Arab, South Asian, African or Central/East European or White British heritage. Our criteria were expanded on advisory group advice, enabling limited comparison with other ethnic groups, people with non-disabling conditions, and people from Scotland and Wales. We recorded conditions at recruitment but grouped them for comparative analyses. The groups 'food-relevant', 'neurodivergent', 'cancer' and 'brain hyperexcitability' (e.g. migraines, epilepsy) followed advisory group advice, and we also used adaptations of the UK Government Statistical Service 'harmonised' themes: mental health, mobility, dexterity, stamina/breathing/fatigue, sensorial (hearing/vision loss), cognitive (intellectual/memory impairment). We included long COVID and other multisystemic conditions (which may belong to more than one group, so that our overall conditions denominator exceeds 271). We recognise the complexities and inadequacies of our categorisations, discussed in a study output (a toolkit). However, our intersectionality approach means these were starting points to be challenged and deconstructed.

Topics across the strands

The three strands considered the same topics, chosen for a holistic understanding of the context of people's lives, their responses to adversity and health and social inequities, their strengths and assets, and effects on their networks:

1. intersectionalities
2. behavioural responses to COVID risk reduction measures by individuals and their formal (e.g. health/social care) and informal (e.g. friends, family, community) support networks
3. access to resources, formal support and care
4. social networks (informal support and care)
5. physical and mental health consequences of the pandemic, coping and attitudes regarding these
6. mental and physical well-being/quality of life as core outcomes
7. local/regional differences in responses linked to policies/interventions and associated impacts
8. future policy.

Theoretical underpinning

This study took a strengths and asset-based approach, underpinned by embodiment models of disability and intersectionality. Our exploration of social influences on health and well-being was framed by the social ecological model.

Analyses

We used corpus linguistics, framework, latent growth modelling and structural equation modelling for outputs reported here.

Findings

Generally strong adherence to COVID-19 containment measures left people feeling lonely and imprisoned, exacerbated in undocumented migrants by deportation fears. However, crowded accommodation, 24-hour proximity to family, economic precarity, and some disabilities prevented adherence for several and created stress. Vaccine uptake was quick for White British participants but those from minoritised ethnic groups hesitated, though most eventually took it. In our review and strand 3 data, the main hesitancy factors were a lack of appropriate information and fear of side effects. White British participants were more influenced by mass media, and minoritised ethnic groups by social media and local communities; misinformation was most common within the Arab and least common within the Central/East European group. Unexpectedly, experience of COVID-19 and community responsibility were not influential. African and undocumented migrants in particular used traditional remedies instead of or alongside the vaccine.

Informal networks shopped or cooked for participants. Food parcels were sometimes culturally inappropriate. Despite generally good medication access, costs of private medication and transport to pharmacies were problematic for some.

An increased treatment burden, combined with symptoms and everyday lifework, reduced patients' capacity to access health care or carry out self-care. They felt abandonment by health care, increased distrust of formal care, and increased dependence on informal relational networks, augmented by COVID-19 fears and unclear information on what people should do. Strand 3 data show that remote services were convenient and efficient but problematic, with no holistic care, a crisis in mental health care, and a disregard for comorbidities and intersecting factors of disadvantage, for example housing needs. Difficulties making GP appointments by phone or e-Consult-style triage were exacerbated in those digitally impoverished, with complex health needs, not fluent in English, and with some specific disabilities. Our data highlighted power differentials, issues with diagnosis and monitoring, and impaired patient–clinician relationships leading to perceived ethnic discrimination and being 'fobbed off'. Some self-medicated instead, or researched coping strategies or online therapy. Several refused face-to-face care when offered it, through COVID-19 fears.

Language, culture, socioeconomic and disability intersections with condition were often not considered in medical care, and so could exclude, cross religious and cultural lines, result in inappropriate and potentially harmful intervention, or destroy clinician–patient relationships with perceptions of discrimination. We found intersections between ethnicity and mental health in perceptions of being fobbed off by health providers. Non-specific appointment times for remote consultations were particularly problematic for those with combinations from among low income, disability, or lack of support networks, child care or English language fluency. Often, service management of expectations would have improved experiences. While the intersection of different minoritising factors tended to worsen experiences, participants with more disabling conditions mostly focused on disability discrimination only.

As a novel contribution, we defined three treatment backlog categories that left people suffering for years, worsening their condition and NHS expectations: deferrals of initial help-seeking processes; secondary or social care waiting lists (including when GP referrals had not progressed in the system due to a lack of capacity); and delays when existing treatment, monitoring plans or social care were reduced or cancelled. These left people in limbo; some took further action to get NHS care.

Many had never registered with a GP, irrespective of residency status, trusting private care more though it was not affordable. Sometimes the private doctor was a family member or friend. A few consulted doctors in their country of origin. Our survey showed community help was most likely to have physical and psychological benefits for those with chronic conditions in 2021, and social and mental well-being benefits in 2022; people reduced NHS help-seeking and increased community help-seeking. NHS help improved their psychological well-being in 2021 and physical well-being in 2022. Our interview data supported the importance of informal social networks for practical and emotional support. Cultural differences in family support, and differences in technology and social media use, including effects on entrepreneurship, empowerment and communication of appropriate information, should be considered in policy and practice.

Psychological well-being was worst in the 'minoritised ethnic–chronic conditions' group in our survey, possibly reflecting poorer access to health care. Sixty-six interview participants had one or more clinically diagnosed mental

ill health conditions. Most had comorbidities, which were disproportionately common in minoritised ethnic groups. Central/East European and African participants were reluctant to seek help for mental ill health because of pride or stigmatisation. Relationships with comorbidity-related job loss and experiences of conflict zones should be disambiguated in studies reporting mental health effects of the pandemic.

Coping was enhanced by combinations of: adequate housing; spirituality; access to green spaces, technology, social support and education; adequate health; knowledge about UK systems; skills; English language fluency; and income stability. Hence, local and national policy should focus on facilitating informal connections, community and individual empowerment, and opportunities for self-care and self-improvement.

Socioeconomic status and diasporic densities were significant intersecting factors by location.

Our survey suggested healthy White British people experience more well-being advantage in England than elsewhere in the UK. Overall, considerations of the transferability of findings should encompass convergences and divergences across our ethnicity, disability and citizenship categories, rather than location.

Mobility and stamina issues intersected with cramped housing conditions, particularly in multigenerational South Asian migrant households. Other important intersectional factors were religion, and economic precarity from pandemic job loss, precarious work (e.g. zero-hour contracts) and reduced work hours intersecting with disability. Several families unexpectedly lost their breadwinners to COVID-19. These issues, combined in 2022 with the cost-of-living crisis, left participants pessimistic about the future.

Citizenship status intersected with socioeconomic status in income, employment prospects, accessing private health care, and feelings of imprisonment. Undocumented migrants and those on non-work visas were particularly affected, unable to claim welfare assistance, and felt imprisoned through deportation fears, but impacts were great for those with visas, due sometimes to a lack of information, or racism.

Issues with online food shopping could result from digital poverty, socioeconomic status and minimum spends, non-familiarity, inaccessible websites, differences to in-person shopping and the person's impairment all intersecting.

Our survey showed that overall, well-being was not significantly affected by 2021–2 COVID restrictions. This contrasts with our secondary cohort analysis for the 2020 first lockdown. We found that while non-disabled people (including from minoritised ethnic groups) recovered after the first lockdown, well-being worsened in disabled people. Perhaps by 2021 people had learnt coping measures, an interpretation supported by our qualitative data. Many strand 3 participants reported loneliness, suicidality and addiction issues caused by lockdowns and other infection containment measures, but there were improvements once the country opened up and the vaccine was available. A few found it hard to readjust. Participant anxieties about contracting COVID-19 from people lax in infection containment measures pertained throughout but escalated when the country opened up in mid-2021.

Several were initially engaged with government action in early 2020, but most ended up critical, due to delays in government action, failure to follow scientific advice, inconsistent messaging, and eventually also politicians breaking rules to suit themselves.

Early in the pandemic, online and in-person shopping were problematic for everyone, but disabled people in the process of being diagnosed and others who had been online shopping for years and were suddenly deprioritised as not on the 'clinically extremely vulnerable' (CEV) list were especially disadvantaged. Eventually, charities got the lists expanded to include other disabilities.

Treatment delays left many in limbo, particularly in later interviews, suggesting the longer the wait, the more likely this feeling was to develop, or that services became less certain later in the pandemic. Existing patients given a revised date were initially less likely to feel in limbo, a novel finding.

Conclusions

We showed that structural adversities cut across minoritised groups, including those often viewed as 'white'. There is a need to look at intersecting factors, specific contexts and individual and community strengths and assets, rather than considering some groups as inherently more disadvantaged. We also showed that low socioeconomic status is a problematic product of racial and disability discrimination that cuts across experiences and groups.

Synthesising our qualitative and survey data revealed an intersection for people of all ethnicities of lower socioeconomic status, mental health, hand loss and mobility issues, lack of outdoor spaces, cramped accommodation or dependency on others to get outside leading to poor psychological and mental well-being. Participants generally mistrusted NHS and social care, preferring informal networks and private care despite the cost. While these challenges have a structural basis, our work shows that relatively simple changes supporting empowerment, social connectivity, self-care, communication and understanding would rapidly improve the lives of disabled people from minoritised ethnic groups. We are developing some ideas for local and regional implementation. We have shown that with appropriate approaches, minoritised groups, including undocumented migrants, can easily be involved in policy and practice decision-making. This would reduce structural barriers and marginalisation, with better care and outcomes for all.

Study registration

This study is registered as ISRCTN40370, PROSPERO CRD42021262590 and CRD42022355254.

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