

Long Covid in ethnic minority populations: ? Lost in translation

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SARS- COV-2 infection can lead to multiorgan systemic damage and prolonged symptoms over many weeks and months termed long COVID or post-acute COVID-19 syndrome. Certain populations, such as the elderly, those with comorbidities, socioeconomically deprived populations and ethnic minorities have been disproportionately affected with COVID-19. Long COVID has also been more prevalent in those who have been disproportionately affected with COVID-19 including those with chronic comorbidities and severe infections. A plethora of long COVID publications have been published over the last three years including several systematic reviews. However, the data on long COVID in ethnic minorities and across intersectionality are lacking and have reported inconsistent findings with some studies showing a higher prevalence and some showing lower prevalence. Furthermore, most published data are from high income countries with varying rates of non-white populations when reported and data from low-income countries for comparison of long COVID rates and symptoms are lacking. One large UK study of 10 longitudinal studies reported that overall odds of long COVID symptoms lasting more than four weeks was significantly lower in south Asian and Black populations. [1] Another large Danish nationwide cohort study using routine data suggested that ethnic minority groups from North Africa, Middle East, Eastern Europe and Asia had significantly greater risk of long COVID compared to native Danes .[2]

Patient-reported outcomes are increasingly collected in clinical trials and in routine clinical practice including long COVID. However, there have been several difficulties in interpretation of these findings due to the differences in symptoms experienced by different ethnic groups. For example, a US study showed that thromboembolism cough, diabetes mellitus, chest pain and acute injury were more common in Black populations while sleep disorders and gastroesophageal reflux disease were more common in White populations [3] Another large US study assessed new symptoms and conditions 31 to 180 days after COVID diagnosis and found that hospitalized Black patients had higher odds of being diagnosed with diabetes, and headaches while Hispanic patients had higher odds of headaches and dyspnoea. Non-hospitalised Black patients additionally

had higher odds of pulmonary embolism and diabetes, while Hispanic patients had higher odds of being diagnosed with headaches or chest pain .[4] Another US study reported that ethnic minorities were significantly more likely to have long COVID although the cognitive symptoms experienced were different, with Blacks more likely to have trouble remembering while Hispanics were more likely to report difficulty understanding .[5]

The differences in these findings have not been well explained, but could be due to several reasons. These include routine electronic database studies not capturing the cultural and sociodemographic aspects of symptom presentations in ethnic minority populations, difficulty in explaining symptoms to non-ethnic minority health care professionals, mis-interpretation of symptoms by health care professions, symptom burden questionnaires used in studies not being culturally adapted. Other explanations include disparities in thresholds for symptoms, with greater psychological distress in ethnic minorities, communication barriers or even a possibility of differences in biological mechanisms. Previous research has suggested inter-ethnic differences in experience of certain symptoms such as musculoskeletal pain with a UK study reporting that there was a fourfold higher reporting of musculoskeletal pain prevalence in South Asians compared to Europeans.[6] Furthermore, the study reported that there were large differences even within South Asian groups because Indians, Pakistanis and Bangladeshis, who make up most of the south Asian groups, are a heterogeneous population.[6] The study also showed that acculturation accounted for some of the differences, but not all, between the ethnic groups. A US study suggested that general physical symptoms are less likely to be reported by Asians compared to White populations). [7] Interestingly, when language was taken into account there were no differences between the ethnic groups, in general physical symptoms .[7] US studies have also reported that Latinos and White ethnic groups had overall similar symptoms, but significantly lower physical symptoms among Asian Americans with acculturation being significantly associated with physical symptoms in both Latino and Asian Americans. [8] Similarly studies have suggested under reporting of depression among ethnic minority populations compared to White patients with pain being more prevalent in ethnic minorities. Under diagnosis of depression could be due to communication

difficulties, health seeking behaviour and potential worry about stereotyping. These differences in symptom presentation may also result in different consultation rates in ethnic minority groups. One large database study in UK using consultations reported that there was increased risk of long COVID in Black Afro-Caribbean and Mixed ethnic groups with people from Asian ethnicity presenting with more broad spectrum symptoms such as pain, fatigue and rashes.[9]

Many symptom-related studies such as for long COVID require use of validated questionnaires. The translation of symptoms across ethnic groups poses significant challenges, including the potential oversight of cultural nuances in routine electronic database studies. Validated questionnaires, essential for studies like long COVID, often undergo forward and back translation for use in multi-ethnic populations. However, these methods may oversimplify the complexities of symptom experiences due to cultural meanings. Efforts to translate questionnaires into different languages necessitate the involvement of translators and focus groups, ensuring not only comprehension but also acceptability among ethnic minority populations. [10]

In summary, studies of long COVID in ethnic minorities have yielded mixed and challenging results and suggest that the symptoms experienced by ethnic minority populations may differ from White populations. To bridge this gap, there is an urgent need for comprehensive studies that explore the prevalence and drivers of long COVID in ethnic minority groups and other under-served populations. Moreover, addressing language and health literacy barriers is paramount to ensuring the accurate representation of these populations in research. These include overcoming challenges encountered in developing and validating questionnaires which will require cross cultural translation of patient reported outcomes questionnaires. This should include comprehensive patient reported outcome assessments in routine clinical care setting and research that is inclusive and equitable. We need to work closely with underserved communities including ethnic minority groups to capture outcomes that matter to them and build trust. We still know very little in terms of long COVID, however, we need to ensure we adequately research long COVID in ethnic minority populations and do not lose the initiative in translation and further widen disparities.

Conflict of interest

KK was Chair of the ethnicity subgroup of the UK Scientific Advisory Group for Emergencies (SAGE) and is a member of SAGE. KK is Director for Centre for Ethnic Health Research, University of Leicester, UK.

KK (Chair), AB, RAE and MC are members of the National Long Covid Research Group that informs the CMO for England.

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