

PROCESS AND SYSTEMS Relationship between ethnicity and multidisciplinary intervention for young people with rheumatic and musculoskeletal diseases

Authors: Aicha Bouraoui,^A James Glanville,^A Samiha Ismail,^B Corinne Fisher,^C Sophia Mavrommatis,^D Maria Leandro,^E Joanna Gupta,^F Stephanie Meyer,^F Peter Shakeshaft,^G Tracey Crissell^H and Debajit Sen^I

ABSTRACT

Introduction

There is growing recognition of the impact of societal factors on health throughout a patient's lifespan. The COVID-19 pandemic has exposed the impact of racial disparity on health outcomes.

Aims

We aimed to investigate the association between ethnicity and the multidisciplinary team (MDT) interventions for young people (YP) with complex care needs.

Method

This retrospective, single-centre, cross-sectional study was conducted within the department of adolescent and young adult rheumatology at University College Hospital, London, between August 2019 and August 2021. We extracted demographic, clinical and laboratory data. The index of multiple deprivation was extracted from the Office for National Statistics database. R software was used for analysis.

Results

We identified 310 YP referred to the MDT with a median age of 18 years (interquartile range 17–19). The female patient to male patient ratio was 2.4. Over a third of our cohort were from deprived areas. Comparison between Black, Asian and minority ethnic (BAME) and White ethnic groups revealed significant differences in terms of referral for pain optimisation ($p=0.006$), social support ($p<0.00001$), and adherence and non-clinic attendance ($p=0.0004$).

Conclusion

Our findings reveal the importance of quality data for early identification and support of vulnerable YP, particularly those from BAME communities.

KEYWORDS: young people, multidisciplinary, social determinants of health, ethnicity

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Background

There is growing recognition of the impact of societal factors on health throughout one's lifespan. Research demonstrates that lifestyles and living conditions have the most impact on disease trajectory and health, as opposed to the healthcare received, which contributes only 10%–20% to population health outcomes.¹

The social determinants of health (SDoH; 'the conditions in which people are born, grow, live, work, and age') are even more impactful among Black, Asian and minority ethnic (BAME) communities.² BAME groups are more exposed to socioeconomic deprivations and structural racism, which can lead to adverse health outcomes.^{3,4}

Despite increasing evidence of the adverse impact of SDoH and ethnicity on health outcomes, there is a limited understanding of the contribution and relationships between these factors and the identified drivers.³

In this retrospective observational study, we aimed to investigate the relationship between ethnicity and the multidisciplinary team (MDT) interventions for young people (YP) managed at an adolescent and young adult (AYA) rheumatology tertiary centre.

Methods

Study design

We conducted a retrospective analysis for all YP referred for rheumatology MDT input in the period from August 2019 to August 2021 at University College London Hospitals NHS Foundation Trust.

We extracted relevant clinical and demographic information. Additionally, with help of the business intelligence team, we collected up-to-date data pertaining to the index of multiple deprivation (IMD) from the Office for National Statistics (ONS).⁵

Authors: ^Aclinical research fellow in adolescent rheumatology, University College Hospital, London, UK; ^BST4 doctor, The Royal Free Hospital, London, UK; ^Cclinical lead and consultant in adolescent rheumatology, University College Hospital, London, UK; ^Dtherapy lead in adolescent rheumatology, University College Hospital, London, UK; ^Econsultant in adolescent rheumatology, University College Hospital, London, UK; ^Fclinical nurse specialist in adolescent rheumatology, University College Hospital, London, UK; ^Ganalyst in business intelligence, University College Hospital, London, UK; ^Hsenior analyst in business intelligence, University College Hospital, London, UK; ^Iconsultant in adolescent rheumatology, University College Hospital, London, UK

Study setting

The study was conducted at a tertiary centre, the department for AYA rheumatology, at University College Hospital. A focus group meeting with YP, representing a spectrum of rheumatic disease, was organised before this study began, with the views of the YP and their families considered in the study design. Ongoing patient and public involvement and engagement is planned to co-design a strategy for service improvement, including MDT input.

The service has an established weekly adolescent pain MDT clinic, supported by bimonthly multi-professional meetings attended by consultants, trainee doctors, clinical nurse specialists, a senior physiotherapist and social workers, aiming to support YP with the most complex needs.

Clinic consultations routinely include psychosocial assessment using the 'home, education/employment, eating, activities, drugs, sexuality, suicide/depression and safety' (HEEADSSS) approach as well as educational achievement. In addition to routine clinical assessment, YP are provided with guidance and support to cope with their disease, mental health and educational needs.

The MDT referral can be made by any member of the team; the patients' consent and, if appropriate, the patients' guardians' consent is always obtained for this. It is extremely rare that patients decline support from our MDT. All YP were referred for one main reason.

Population

In line with the World Health Organization, YP were defined as those aged 10–24 years.

Statistical analysis

The dataset collected was analysed using R software (R version 4.0.4). The median and interquartile range (IQR) were calculated for continuous variables, and the frequency and percentage for categorical variables. Subgroup comparisons were performed using the chi-squared test for categorical variables. P values less than 0.05 were considered significant and less than 0.01 as highly significant.

Ethics

This study analysis was conducted using fully anonymised data. In accordance with Health Regulation Authority (HRA) requirements in the UK, patient consent was not required.

Results

Baseline characteristics

Of 1,373 YP identified, 310 were referred to the MDT. The mean monthly number of YP discussed at the MDT in the years 2019, 2020 and 2021 was 15, 8 and 19, respectively. This variation could reflect the impact of the COVID-19 pandemic on service provision.

As summarised in Table 1, YP referred to the MDT were younger, with a higher proportion of White YP compared with the whole cohort. The underlying diagnosis was predominantly that of primary chronic pain. Over two-thirds of YP referred to the MDT were from deprived areas (40%), which is representative of general YP clinic cohort (43%).

Table 1. Demographic characteristics in the total young people clinic population and young people referred to the multidisciplinary team

Characteristics	Adolescent and young adult total clinic population	Adolescent and young adult referred to multidisciplinary team
Total number	1,373	310
Female patients, n (%)	942 (68)	221 (71)
Male patients, n (%)	431 (32)	89 (29)
Age, median (IQR)	19 (17–21)	18 (17–19)
Black, Asian and minority ethnic, n (%)	563 (41)	128 (41)
White, n (%)	810 (58)	182 (59)
Young people from deprived areas, n (%)	590 (43)	124 (40)
Juvenile idiopathic arthritis, n (%)	783 (57)	85 (27)
Other connective tissue diseases, n (%)	325 (23)	14 (4)
Chronic pain, n (%)	275 (20)	150 (48)
Young people with more than one long-term condition, n (%)	370 (27)	29 (9)
Depression/anxiety, n (%)	147 (10)	55 (17)

Indications for referral

The main indications for MDT referral (Fig 1) were YP requiring optimisation of pain management for 31% (n=96), consideration of further clinical investigations/specialist referrals for 21% (n=65), mental health support for 17% (n=51) and social support for 13% (n=39). Additionally, in 13% (n=31), concern was raised about their infrequent attendance for clinic appointments and/or infusion treatment, 3% (n=11) had unmet expectations in managing their symptoms and 1% (n=5) were reported by YP and/or parents at risk and vulnerable to the use of drugs and alcohol.

Variation in ethnicity

Comparison between BAME and White ethnic groups revealed statistically significant differences in terms of referral for pain optimisation (28 vs 68, respectively; $p=0.008$), social support (31 vs 8, respectively; $p<0.00001$) and poor attendance (22 vs 9, respectively; $p=0.0006$). There were no statistically significant differences in terms of other MDT inputs. The results are shown in Table 2.

Discussion

The COVID-19 pandemic has exposed the severe impact of racial disparity on health outcomes. As described in the COVID-19

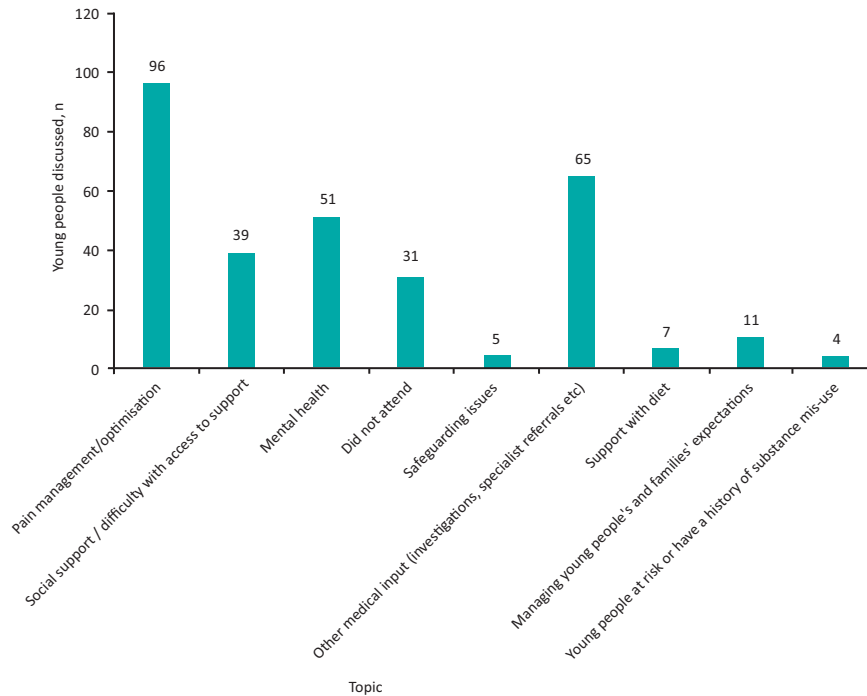


Fig 1. Young people discussed per topic at the multidisciplinary team meeting.

Marmot review, decades of inequality within England led to the worst COVID-19 infection and mortality rates in Europe, and there is an urgent need to acknowledge the impact of racism and ‘adverse distribution of socioeconomic characteristics’ on health outcomes.⁷ The pandemic has also shed light on institutional racism and its impact on YP health outcomes; for example, disproportionate exposure to job losses and pay cuts among BAME families during

the pandemic have the potential to adversely impact long-term physical and mental health. We think it is of paramount importance for health systems to proactively identify vulnerable groups to address inequality in health outcomes.

Addressing inequality is even more crucial for YP, where the challenges of life as an adolescent can be markedly different to other age groups, thus making YP particularly vulnerable to the SDoH and racial disparity.⁸ A recent scoping review identified significant racial disparity in childhood cancer survivors’ health outcomes (poor survival and increased healthcare utilisation) in Hispanic and non-Hispanic-Black YP compared with non-Hispanic-White YP. Hence the importance of trying to integrate comprehensive SDoH variables (ethnicity, education level, family structure, neighbourhood and deprivation level) in healthcare systems caring for YP.⁹ Similar findings have also been noted in cardiometabolic outcomes in YP from BAME backgrounds.⁴

This case study aimed to investigate the relationship between ethnicity and MDT support for YP, and to make a case for the need to integrate standardised SDoH screening tools, tailored to YP, in routine clinical care. The COVID-19 pandemic has had a significant impact on service provision, with reduced numbers of patients referred to the MDT. This fell by 50% in the first year of the pandemic and, therefore, this period may not truly reflect pre- or indeed post-pandemic practice. The increased use of telephone consultations to continue clinical support during the crisis, along with significant staff redeployment to the patient-facing roles could explain why the numbers of referrals fell during this time. The lack of data investigating the true impact of COVID-19 on service provision is a limitation of this study.

Linking in with ONS data, we have shown that a high proportion of YP referred to the MDT were from deprived areas. Only 12% of our cohort, however, were referred to the MDT for social support. This could be an underestimation as our study was limited by the retrospective collection of data (using the MDT referral letter and

Table 2. Comparison of multidisciplinary team patients’ needs

	Black, Asian and minority ethnic, n= 128, n	White, n= 182, n	p-value
Pain management optimisation	28	68	0.008
Social support	31	8	<0.0001
Mental health	16	36	0.15
Did not attend	22	9	0.0006
Safeguarding issues	1	4	0.62
Other medical input (investigations, specialist referrals etc)	24	41	0.58
Support with diet	1	6	0.29
Managing family expectations	2	9	0.21
History of substance misuse	1	3	0.89

the documentation from the MDT) meaning that more detailed information pertaining to a need for social support may not have been captured, and there is variation in capturing and recording all psychosocial factors using the HEEADSSS approach, which is an issue that has been raised in previous studies.¹⁰ This study is further limited by the lack of standardisation in the MDT referral form and in the related documentation, consequently affecting the data collection pertaining to this that is currently extracted using narrative data.

In addition, the MDT referral is based mainly on healthcare consultation outcomes and information expressed by patients and their carers during the consultation, meaning information regarding social circumstances may also not be captured in detail. Finally, the underestimate could be due to patients' or carers' reluctance to disclose concerns, the reasons for this are likely to be multi-factorial.

Aligning national data (like the ONS database) to hospital data, along with using SDoH screening tools, could potentially lead to early identification and, thus, provision of support for vulnerable YP. Furthermore, including occupational therapist and a hospital-based youth worker could complement the role of the wider MDT to wrap resources around the needs of the YP.

We investigated the correlation between ethnicity and MDT input in our cohort. Interestingly, this revealed a significant difference between BAME and White ethnic groups, with a higher proportion of White YP referred to the MDT for optimisation of pain management. This could be due to White YP more explicitly asking for pain relief and varying healthcare beliefs among different cultures, or possibly variation in the documenting clinicians' interpretation of the YP pain experience.

A study from the USA investigating the association between clinicians' beliefs and racial disparity in pain management between White and Black African American patients (YP and adults' cohorts), revealed that clinicians' medical judgement may be influenced by beliefs surrounding biological differences between Black and White patients, which, in turn, may contribute to unintentional racial disparities in pain management.¹¹ Similar findings have also been noted in other studies.^{12,13}

Interestingly, in our cohort, there was no statistically significant difference between White and BAME YP in terms of MDT referral for mental health support. However, a significantly higher number of BAME patients were referred for social support. This is consistent with national figures. Specifically, one recent ONS report revealed that BAME children and adolescents, particularly from Black, Asian (mainly Pakistani and Bangladeshi background) and mixed ethnic groups, were more likely to suffer social deprivation compared with those living in White households.¹⁴

Regarding concern about infrequent clinic and day care attendances, this was noted to be higher among BAME YP compared with White YP, possibly due to combination of societal and cultural factors. A systematic review investigating disparity in the quality and safety of care received by ethnic minorities (including adults and YP cohorts) revealed that the contributing factors to poor experience of care included language barriers, patients' cultural and healthcare beliefs surrounding both treatment and disease, and the degree of engagement and interactions with health professionals.¹⁵

Conclusion

Over two-thirds of YP referred for MDT input were from deprived areas. YP from BAME backgrounds required more social support

and had worse attendance but were less often referred for pain optimisation. In the context of the COVID-19 pandemic, there is an urgent need for comprehensive screening tools of SDoH, particularly in BAME individuals underpinned by standardised use of existing psychosocial tools, such as HEEADSSS.

We have identified a pressing need for quality data to understand the drivers of poor health outcomes, enable early identification and support of YP with specific needs. ■

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Address for correspondence: Dr Aicha Bouraoui, University College Hospital, 250 Euston Road, London NW1 2PG, UK. Email: aicha.bouraoui@nhs.net