Testing the waters

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Testing the waters: Covid 19 first wave and shielding among BAME patients with rheumatological conditions in United Kingdom

Introduction:

The world is currently in the grip of coronavirus pandemic which started in China at the end of 2019 and then spread across the world with more than 53 million infections and 1.3 million deaths (World Health Organisation, 2020). United Kingdom (UK) currently reports world's fifth highest death toll with more than 50,000 deaths (and counting). COVID 19 is a new infection with limited information of risk factors for severe disease. People with autoimmune conditions that were being treated with immunosuppression were considered vulnerable, and UK government issued guidance asking people on immunosuppression to take extra precautions - social distancing everyone, and 'shielding' (shielding is a measure introduced to protect those at very high risk of severe illness by minimising all interaction between them and others) for the most vulnerable patients (https://www.gov.uk/government/news/major-new-measures-to-protect-people-at-highest-risk-from-coronavirus, 2020). British Society for Rheumatology (BSR) created a risk algorithm to define rheumatology patients at highest risk ((risk stratifications core of 3 or more) and needing to shield (Price at al, 2020). These measures were introduced in March, and continued till August. Shielding advice and guidance was publicised in media and on the government's web portals (https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19, 2020). Scoring according to risk stratification guide takes into account medications – the highest score is for Prednisolone 20 mg or higher for 4 weeks or more as well as any Cyclophosphamide use in the last 6 months, these score 3. Lower doses of Prednisolone between 5 and 20 mg score 2, while conventional synthetic disease modifying agents (DMARDs) score 1 except for sulfasalazine or Hydroxychloroquine which do not score. Biological DMARDs score 1, the combination of conventional synthetic and biological DMARD scores 2. Co-morbidities such as age >70 years, Diabetes Mellitus, lung disease, kidney disease, heart disease or high blood pressure score 1 each. Patients having a total score of 3 or more were advised to shield. Whilst active rheumatological disease is also thought to contribute to infection risk, this was too difficult to be able to incorporate into an algorithm.

Initially, guidance was provided in English language only, subsequently written information was gradually uploaded in 30 other languages. Black, Asian and Minority Ethnic (BAME)

populations in UK have been disproportionately affected by Covid 19, and death rates had been higher in these communities (Kumar et al, 2020). Investigation by the UK Public health Department found a number of factors including population density, extended family structure and increased exposure from occupations as contributory although more detailed studies were recommended (Disparities in the risk and outcomes of Covid 19, 2020). There are ongoing studies seeking to understand this disproportionate impact further. A number of rheumatology centres with large BAME communities in UK recognised through departmental helpline calls that patients from these communities were unclear about shielding (Kumar et al, 2020). Hence, the authors set up a pilot audit to assess the understanding and practices of shielding within BAME communities.

Methods:

This audit was performed in three units – Royal Wolverhampton NHS Foundation Trust, University Hospitals of Leicester NHS Trust, and Oxford University Hospitals NHS Foundation Trust. This audit was approved in all three Trusts and data were collected from patients during advice line calls or routine clinic appointments. A questionnaire was developed to capture important data on shielding. The questionnaire included their rheumatological diagnosis, comorbidities, current medications, changes to medications, precautions they were taking relating to Covid 19, symptoms of Covid or flare that they had experienced and also to rate the support they had received from friends and family and healthcare professionals. No interpreters were utilised for this study. Scores as per the risk algorithm and judgements about need for shielding were based on the details provided by the patients during the calls.

The audit was conducted between May and June 2020 during the peak of first wave of the coronavirus pandemic in the UK.

Results:

We recruited a total of 79 patients, of these 54 were from BAME communities (52 of these had South Asian heritage) and 25 were Caucasian. This included 30 patients from Oxford, 24 patients from Wolverhampton, and 25 patients from Leicester. The male:female ratio was roughly 1:4 (17:62). Rheumatoid Arthritis (RA) was the commonest diagnosis in 49 of these patients (62%) and these patients were older (median ages 56 vs. 46 years, p=0.14).

BSR risk scoring algorithm was used to determine need for shielding (BSR score of 3 or more) – 38 patients fell into this category. The remaining patients had scored lower and had the option of shielding or enhanced social distancing. Of the 13 Caucasian patients who should have been shielding, 11 were (85%). Of the 25 BAME patients who should have been shielding: 17 were, and 8 were not (68%, p=0.26).

Understanding of reasons for shielding was clear for 21 out of 25 Caucasian patients (84%) compared to 33 of 54 patients from BAME backgrounds (61%, p=0.10). Within Wolverhampton and Leicester, the numbers are starker with 20 out of 37 (54%) being clear. Few Caucasian patients made changes to their existing medications with 84% carrying on as they were before COVID 19. However, of 54 BAME patients, 14 patients had stopped medications – either by themselves or on advice of health professionals (74%, p=0.16). There was a significant difference between centres with patients from Leicester much more likely to stop medications ($p<0.001$). Five patients (1 Caucasian and 4 S Asian) admitted to stopping medications by themselves; whilst 13 patients stopped it on advice from a health professional. Flares were experienced in 12 patients, 5 from BAME backgrounds and 7 from Caucasian backgrounds. Total of 10 patients across the 3 sites had experienced symptoms that they had attributed to Covid, although none of these patients were tested. All patients felt that they had good support from friends and family during this period, and all but one patient felt that they had good support from their healthcare professionals.

Discussion:

Covid 19 has posed unprecedented challenges in this era for healthcare provision, and remains the number one global health priority. BAME populations in UK are more vulnerable to this (Disparities in the risk and outcomes of Covid 19, 2020), and although information in English was provided, clear guidance in Hindi and explanatory videos were lacking. Some leaflets in S Asian languages were made available further down the line. This had led to a number of calls to rheumatology helplines. Overall, the patients did rate the support they received from both friends and family as well as health professionals highly. Nonetheless, this audit shows differences in shielding between Caucasians and BAME patients during the first wave when this audit was conducted (although numbers are small). There were also differences in how people dealt with this, BAME patients were much more likely to stop medications (or be advised to stop medications) perhaps due to fear and anxiety, putting

themselves at further risk. There also appear to be significant differences in how different units are dealing with this. Anecdotally, we are aware of a number of units that have been trying to reduce medications for patients. Since disease activity has not been included in the risk algorithm, this might be subconsciously biasing health professionals against drugs. We are also aware of number of patients from all 3 sites who have delayed their usual treatments or new therapies due to anxiety about the risks despite their underlying condition flaring!

Differences in rheumatological disease outcomes among BAME populations are well recognised. Previous studies have shown that BAME communities are less likely to seek medical help at the onset of symptoms and also to adhere to self-management programmes (Kumar et al, 2010). Also, we have previously identified several barriers to treatment access and adherence (Kumar et al, 2015). Addressing the educational needs of the rheumatological BAME population continues to remain a challenge and is likely to exacerbate inequalities in these challenging times with further outbreaks of Covid 19. A much more inclusive programme is needed and this needs attention as a priority.

Key message:
Rheumatological BAME patients in UK have failed to fully understand the importance of shielding.

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