Multiple Myeloma In Black African and Caribbean Communities

An AHPN Briefing Paper

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The AHPN is a national health policy organisation, working with and within diverse African communities across the UK to improve the health and wellbeing of Africans. Our aim is to reduce health inequalities for African people in the UK. We work to ensure that this aim, to achieve greater equality in health, is shared and prioritised by government and statutory agencies now and in the future. In the wake of the Marmot Review into health inequalities and the Health and Social Care Act 2012, and the mapping out of the Public Health Outcomes Framework (which sets out the desired outcomes for public health in England and Wales and how these will be measured) we find that our presence is as necessary now as it has always been. The two high level outcome objectives across all of public health are:

- Increased healthy life expectancy
- Reduced differences in life expectancy and healthy life expectancy between communities

The former reflects a focus not just on how long individuals live but also the quality of their lives, at all its stages. The latter is concerned with reducing health inequalities between people, communities and geographical areas (Department of Health, 2012). In policy terms there is no better time than now to work to achieve greater health equality.

The focus of AHPN’s work encompasses a range of health conditions that disproportionately affect Africans in the UK: cancer, diabetes, HIV, mental health, stroke and TB. AHPN also works to address the wider determinants of health, including structural, individual, social, cultural and economic factors. Our policy work is predicated on the concept of intersectionality – that experience is defined and shaped by the multiple strands of roles and influences that make up the identities that individuals possess and how these intersect, and the multiple factors that influence their lifestyles, options and opportunities.

This intersectionality of experience is the key to understanding the root causes of health inequalities between and within communities, and this informs our work on health issues such as multiple myeloma.
**Background**

Myeloma is the 16th most common cause of cancer death in the UK with most deaths occurring among the elderly (Cancer Research UK, 2015). Every year in the UK, about 4,800 people are diagnosed with myeloma with the average diagnosis age of 73 years (Basil Skyers Myeloma Foundation, 2015; Myeloma UK). However, recently, the development of myeloma was also observed among people aged 30 to 50 years and presently, there is an increase in the incidence rate of this disease within this age group (Basil Skyers Myeloma Foundation, 2015).

Multiple Myeloma (MM) also known as blood cancer is the second most common form of blood cancer caused by increased malignant bone marrow plasma cells (Rollig, Knop and Bornhauser, 2015). This proliferation results in multiple numbers of malignant cells out numbering the normal plasma cells that fight disease infection. This subsequently leads to the secretion of monoclonal immunoglobulins which is identifiable in the urine or serum. (Rollig, Knop and Bornhauser, 2015).

In Addition to proving fatal, MM can lead to serious complications including renal failure, spinal cord compression and pathological fractures (Cancer Research UK, 2015). Common symptoms of multiple Myeloma are anemia, infections, Osteopenic bone disease and renal failure (Rollig, Knop and Bornhauser, 2015). Early symptoms are back pains and unclear anemia (Rollig, Knop and Bornhauser, 2015).

**Risk factors**

Little is known about the risk factors predisposing people of African and African Caribbean origin to MM in the UK. Reasons underlying this may include the fact that it is a relatively less common disease (1% malignancy), and a challenging one to diagnose due to the similarity of its symptoms (bone or muscle pain, numbness etc) to other diseases’ (Multiple Myeloma Research foundation (MMRF), 2015). Also, there seems to be a general lack of awareness of the increased risk of the disease faced by Black people among health professionals and members of this population (Rochman, 2014). Finally existing epidemiological studies and clinical trials on multiple myeloma involving Black people also
remain limited worldwide (Skyers and Kendall, 2015), weakening certainty on causality between exposures of interest and the disease. Nonetheless, a growing body of evidence, predominately from the US, seems to link the increased rates of MM among Black people to demographic factors whilst links to environmental influences and their possible interactions with the former factors remain unclear.

**Race** as highlighted plays an important role with Black people having the highest risk of developing MM than any other race or ethnic group worldwide. In the UK specifically, MM incidence among African and African Caribbean men and women is twofold that of their White counterparts and has been the case for the past 40 years (Skyers and Kendall, 2015).

**Age** is another key risk factor for the blood cancer. Though MM mostly affects people aged 65+ (Cancer Research UK, 2015), incidence data disaggregated by age and race from a study by Waxman et al (2010) suggests myeloma to occur at least 4 years earlier in Black people than White people (Waxman et al, 2010). These trends are alarming for black people in the UK. Not only has the onset age for myeloma generally declined in recent years it is also estimated that by 2026 13.4% of the African Caribbean population in the country will be aged 65 and over, the second highest proportion after the white Irish population.

**Gender** has been significantly linked to MM among Black people. Cancer statistics from the National Cancer Intelligence Network and Cancer Research UK indicate that age standardised MM rates for Black males range from 10.9 to 18.2 per 100,000 compared to 6.1 to 6.5 per 100,000 among white males and 3.6 to 6.4 per 100,000 among Asian men (NCIN, 2009). Furthermore, risk of disease is also higher among Black men than Black women with the latter's rates ranging from 6.6 to 11.5 per 100,000 (NCIN, 2009). Black women are still more predisposed to MM than Asian women (2.3 to 4.4 per 100,000) (NCIN, 2009). Evidence suggests monoclonal gammopathy (MGUS) of uncertain significance, a premalignant condition, to be a potential driver of the higher prevalence of MM among Black people. Indeed MGUS reviews of MGUS prevalence in 14 studies have revealed Black people in the US to be approximately twice at risk of MGUS than White people i.e (5.9% – 8.4%) vs (3.0% – 3.6%) (Skyers and Kendall, 2015). A study of Ghanaian men in Ghana by Landgren et al (2007) further reflected these findings suggesting the potential role of genetics (Landgren et al, 2007). Yet it should be noted that there is no evidence of higher progression rates from MGUS to MM among Black people (Bird et al, 2014).
Large population studies from Europe and the US point to considerable associations between HIV/AIDS and elevated risks of MM though the causal pathways are not fully understood. For instance in England, Newnham et al (2005) used data from the thames cancer registry and the national HIV database to reveal that standardised incidence ratio for MM in a sample of 26,080 HIV positive people was significantly higher (2.70 with 95% CI: 1.00 – 5.94) (Newnham et al,2005). This is problematic as African and African Caribbean people in the UK are disproportionately affected by HIV/ AIDS and thus are at increased risk of MM.

Likewise, being obese or overweight, conditions highly prevalent in the Black population in the UK and beyond, has been linked to greater risk for MM. For instance, Hofman et al (2013) found that MM risk was associated with increasing body mass index (BMI) at cohort entry (per 5-kg/m(2) [hazard ratio (HR) = 1.10, 95% confidence interval (CI): 1.00, 1.22] (Hofman et al,2013). These associations remained consistent at 50 and 18 years of age.

Finally, a small number of studies in the US have reported positive links between higher socioeconomic status and increased MM risk especially among African Americans (Birmann et al, 2012). Yet this should be interpreted cautiously due to selection bias and lower representation of African Americans of low educational and socio economic status in research.

Multiple Myeloma related Morbidity and mortality

Current data show that 1,333 males and 1,116 females died from the disease in England and Wales in 2013 (Skyers and Kendall, 2015). To date however national mortality statistics for MM by ethnicity are nonexistent in the UK making it difficult to map disease burden among African and African Caribbean people. A recent study by Samy et al (2015) estimated survival rates by ethnicity using 2002-2007 data from the national data cancer repository. Interestingly, it found risk of death to be less among Black people at 1 year survival HR=0.65 (95%CI 0.51-0.82) and 3 year survival HR=0.71 (95% CI 0.57-0.87), compared to White patients (Samy et al, 2015). This is further supported by data from the US (SEER, 2015).

Furthermore, due to higher prevalence of MM in Black people, death rates are presumably higher in this population. Though there is no conclusive evidence, important socio economic determinants preventing equal access to prevention diagnosis and treatment are further likely to contribute to racial discrepancy in outcomes for MM. Delayed presentation, lack of
awareness about the cancer and deprivation are all consistent characteristics of Black people’s health in England and have been found to be linked to increased chances of MM complications and reduced disease free survival (Kariyawasan et al, 2007).

NICE guidance for the diagnosis and management of MM is expected to be published in February 2016. Whilst the developing guideline acknowledges the vulnerability of Africans and African Caribbeans to MM it claims no specific considerations should be put in place for them (Skyers and Kendall, 2015). This is problematic as the limited evidence highlighted above would suggest the opposite. It is thus pivotal to build a knowledge base on risk factors predisposing Africans and African Caribbeans in the UK to MM in order to understand the aetiology of the disease, the needs and experiences of African and African Caribbean people affected by MM and commission appropriate evidence based interventions to tackle the specific social and structural factors that frame their health outcomes for MM in the UK.

AHPN’S view

Since the launch of the Department of Health’s ‘Improving Outcomes’ initiative to better health outcomes for cancer in 2011, a progress report published last year reveals that survival rates for myeloma, five years after diagnosis, have witnessed the sharpest increases between 2007 and 2012 (3.9% for men and 4.6% for women). Yet due to lack of national statistics by race and ethnicity for Multiple myeloma, it remains difficult to map the disease burden among African and African Caribbean people and assess whether they have been able to take advantage of progressive measures. Given the higher prevalence of the blood cancer among this population, death rates are presumably higher. Important socio economic determinants preventing equal access to prevention diagnosis and treatment are further likely to contribute to racial discrepancy in outcomes for Multiple myeloma. Indeed delayed presentation, lack of awareness about the cancer and deprivation are all consistent characteristics of Black people's health in the UK and have been found to be linked to in-creased chances of Multiple myeloma complications and reduced disease free survival.

In this light, AHPN believes much remains to be done on epidemiological data collection, understanding the aetiology of the disease and the needs and experiences of African and African Caribbean with regards to Multiple myeloma in the UK. Appropriate programs and
services that address the disparities this group faces in the UK should be commissioned and championed.

We welcome NICE guidance for the diagnosis and management of Multiple myeloma expected to be published in February 2016 which recognises the vulnerability of African and African Caribbean to Multiple myeloma. Yet we remain concerned by its claims that no specific considerations should be drawn for any group.

To support the ‘Improved Outcomes’ strategy’s vision, AHPN urges for the guidelines to make provisions for specific considerations to be put in place.

- As the African and African Caribbean population develop multiple myeloma on average four years earlier than the general population, easy access to screening at a younger age should be available and be made common practice in GP surgeries.
- Early diagnosis of multiple myeloma reduces the likelihood of patients entering treatment through emergency services and consequently holding a negative perception of services however if a patient does enter treatment through this route, practitioners should be trained to be culturally competent and capable of providing care that takes into consideration the patients unique needs.
- Multi agency community based efforts to increase early and equitable access to and delivery of screening, swifter diagnosis and treatment is key to reducing morbidity and mortality rates in population.
- Improving knowledge and awareness of the disease among the African and African Caribbean population in the UK is imperative to reducing mortality rates. It is vital that cross platform campaigns are run informing the target population of their disproportionate risk of developing multiple myeloma.
- Promoting healthy lifestyles with particular attention given to black men and women who are obese.
- Improving myeloma monitoring and surveillance data collection desegregated by race and ethnicity.
- An increased effort to include African and African Caribbean people in clinical trials and epidemiological studies in order for data collected to be representative of the population it affects.
References:


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