Caring for People with Cancer from Black and Ethnic Minority Groups

Executive Summary

1. Introduction

• This study was commissioned by Macmillan Cancer Relief to provide insights into the views and experiences of nursing and other staff caring for patients with cancer from black and ethnic minority groups;

• A total of five focus groups were held in London, Birmingham and Manchester, involving 28 people; these were primarily nurses, but included other staff, such as social workers;

• The participants had experience of working with patients from a wide variety of areas, including Africa, the Indian sub-continent, the Caribbean, Eastern Europe and others;

2. Language difficulties

• An inability to communicate with non English-speaking patients created barriers between staff and their patients at crucial points, including diagnosis, treatment and palliative care, and made it difficult for relationships to be formed with them;

• Not knowing what a patient understood, including the diagnosis, prognosis and side effects of treatment, was a major problem for nursing and other staff;

• Written information for patients in their own language was a partial solution, but many patients could not read;

• Some had excellent experience in obtaining and working with interpreters, but many had problems of access to interpreters, especially at short notice;

• Interpreters were sometimes reluctant to translate ‘bad news’ and could omit crucial information, creating problems for staff in their relationships with patients and family;

• There was concern about the impact of this work on interpreters, as they were not generally trained in working with very ill people and might not have ready support;

• Where family members carried out translation, this also created barriers, especially where they decided what information was appropriate to give; this caused dilemmas for staff who felt they needed to work with the family, but had a primary loyalty to the patient;
• Some protective families kept staff at arms length from a patient; staff feared that this meant that they were less able to offer an equitable service to these patients.

3. Cultural differences

• Participants enjoyed learning about new cultures and tried hard to fit their care within the context of different customs; it was seen as impossible to memorise all the information they could need and some had experience of accidentally breaching cultural norms at some point;

• Responding to different cultural and religious practices, as well immigration problems, could prove the source of practical and emotional difficulties for staff; this also meant that working with patients from ethnic minority groups could be very time-consuming;

• Staff felt that they needed to be cautious in making assumptions about patients from ethnic minority groups, as these did not necessarily follow the anticipated religious or other customs;

• Particular discomfort was experienced where staff disapproved of patients’ decisions, for instance to refuse treatment, as this caused conflicts with their professional principles;

• Staff expressed some concerns around patients’ wish to return to their country of origin when they were close to death; some left this too late, so that they were unable to see close family, and others were returning to areas where they would be unable to obtain proper medication;

• While some thought that more staff should be recruited from ethnic minorities, to help patients from the same community, others argued that staff from the same background might make cultural assumptions even more easily; patients often did not wish to be cared for by someone from their community, for fear of gossip within it.

4. Issues of Racial Bias

• Most participants were certain that there was no element of racial bias in their own work with black and ethnic minority groups, although a small number admitted that they did feel differently towards some groups in their day-to-day life;

• Some had negative responses to having taking new patients from ethnic minority groups onto their caseload, based on their experience that they would be difficult and time-consuming to manage;

• Participants also agreed that professionals did not always like all their patients, for all kinds of reasons, and they needed to be alert to this issue;
• Some patients believed that they were receiving poorer treatment because of their race or ethnicity and some made direct accusations of racial prejudice;

• Racism among patients towards staff or other patients was widely seen to be a problem, involving both white patients and bias within the black and ethnic minority community against different nationalities;

• Such racism manifested itself both in offhand remarks and in direct requests not to be treated by certain staff; this was difficult for all staff to handle, as they did not want to collude with such views, but needed to maintain a relationship with patients.

5. **Recommendations**

• Participants would welcome training to help them to explore their attitudes and assumptions in working with patients from black and ethnic minority groups;

• There was little interest in training about detailed practices of different cultures; this was dry and difficult to remember and individuals did not necessarily follow such practices in any case;

• Training should involve short one or two day courses, of varying complexity, which staff might attend on more than one occasion to update themselves;

• Training videos were seen as a useful start, serving as a stimulus about how to handle particular situations, but would not be sufficient on their own;

• Some participants felt they would benefit from training in working with interpreters and some thought that training should be provided for interpreters;

• Most participants felt that they had adequate support mechanisms, although those who worked on their own felt they could benefit from more support;

• Macmillan Cancer Relief should improve its own image with respect to cultural diversity, including the appointment of more post-holders from black and ethnic minority groups; it might also employ specialist interpreters to work with staff and offer telephone advice.

6. **Concluding Reflections**

• The principal finding of this study is the extent which staff experience difficulties in caring for patients from black and ethnic minority groups; these entail serious challenges to their own professional practice, in addition to practical problems of communication.