The use of "informal death" information in lung cancer survival analysis of ethnic groups

Ruth H Jack, Elizabeth A Davies, Henrik Møller

Thames Cancer Registry

Background

An "informal death" is defined as one where a death is recorded on the NHS Care Records Service (CRS), but no formal death certificate has been issued. This may be through a relative or a GP practice contacting the hospital to inform them that a patient has died. This may be more likely if the death occurred outside of the UK. This study investigated the effect of these deaths on male lung cancer survival in different ethnic groups.

Methods

Data on 25,687 males resident in South East England who were diagnosed with lung cancer between 1998 and 2003 were extracted from the Thames Cancer Registry. Patients were followed up until 31/12/2006, and those diagnosed from a death certificate only were excluded.

Men originally recorded as still alive at the end of follow-up were matched to the NHS CRS, and death information from the same period was extracted. Overall survival was examined using the original (based on death certification) and updated (including informal deaths) death data, adjusted for age, socioeconomic deprivation, stage of disease and treatment. Results are reported for White, Indian, Pakistani, Bangladeshi, Black Caribbean, Black African and Chinese men.

Results

Results from the fully adjusted survival analysis using the original death data are shown in Figure 1. Bangladeshi men had better survival estimates compared with White men (hazard ratio (HR)=0.46, p<0.001). Indian (HR=0.84, p=0.048), Black Caribbean (HR=0.87, p=0.47) and Black African (HR=0.68, p=0.007) men also had better survival estimates.

Figure 2 shows the proportion of patients originally recorded as alive at 31/12/2006 in each ethnic group that had updated death information. The largest proportion of patients was in the Bangladeshi group (13/27, 48%). High proportions were seen in the

Figure 1: Hazard ratios and 95% confidence intervals for overall survival in male patients diagnosed with lung cancer, adjusted for age, socioeconomic deprivation, stage of disease and treatment received. White men used as baseline. Original death data used
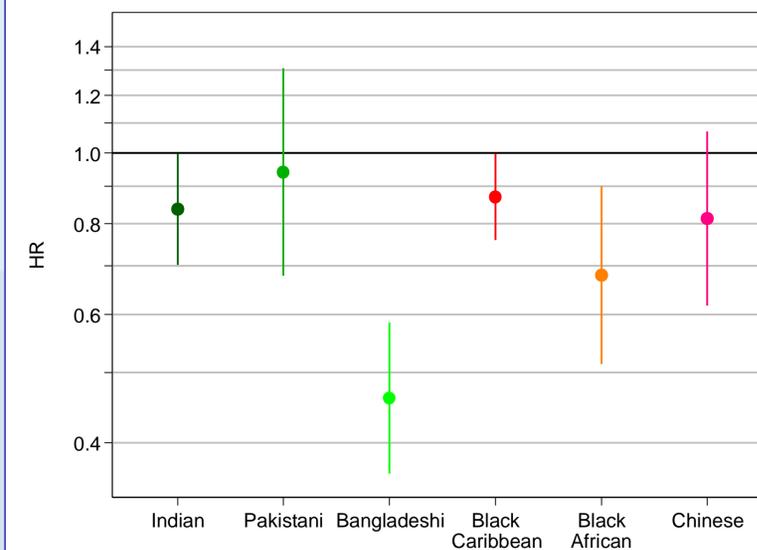

Figure 2: Proportion of men originally recorded as alive at 31/12/2006 with updated death information

Figure 3: Hazard ratios and 95% confidence intervals for overall survival in male patients diagnosed with lung cancer, adjusted for age, socioeconomic deprivation, stage of disease and treatment received. White men used as baseline. Updated death data used
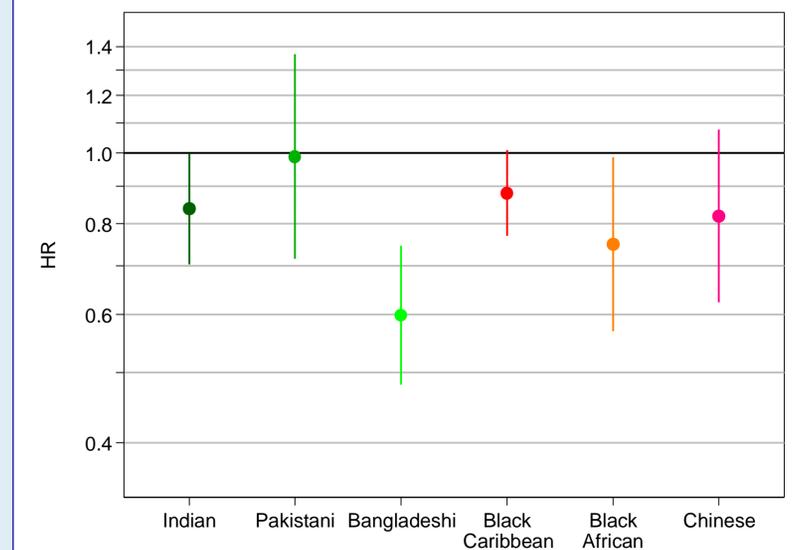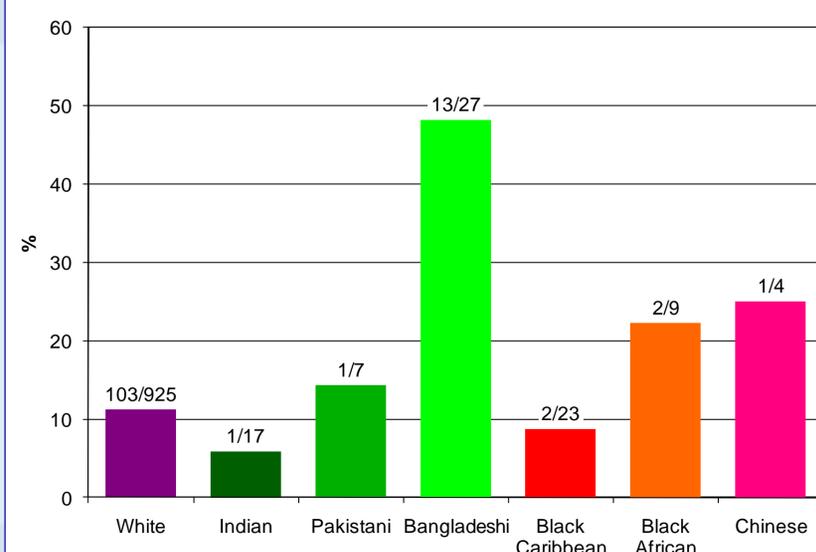
Black African and Chinese groups due to the small number of patients originally recorded as alive (9 and 4 respectively).

Repeating the survival analysis using the updated death information had little effect on the hazard ratios for most ethnic groups (Figure 3). While the Bangladeshi group result was attenuated to HR=0.60 (p<0.001), it was still statistically significantly better than the White group estimate.

Discussion

Routinely used formal death information from death certification does not capture all deaths, and the extent of this varies by ethnic group. Ascertainment of informal deaths reduce the proportion of survivors and the differences between ethnic groups. It is not known whether any more patients have in fact died, but were never recorded as either a formal or informal death, and are therefore lost to follow-up. Comparison of lung cancer survival between ethnic groups may benefit from active verification of vital status.