



Original Article

Cancer of Unknown Primary: a Cancer Registry Study of Factors Affecting Access to Diagnosis

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Received 4 April 2016; received in revised form 11 August 2016; accepted 23 August 2016

Abstract

Aim: A potential impact of the centralisation of cancer services in the UK is difficulty in gaining access for members of the population living far from them. This could lead to delayed presentation of cancer with more advanced disease and clinical deterioration at diagnosis. A patient may be recorded in the cancer registry as having cancer of unknown primary (CUP) if the clinical state at presentation precludes investigation. Other patients may be so recorded if investigation identifies sites of metastatic tumour but the primary is not found. We hypothesised that the first group would include more patients who experienced difficulties in gaining access to health services through residing in deprived areas or through poorer geographical access to healthcare facilities.

Materials and methods: We compared the diagnosis of CUP with a comparator tumour, carcinoma of the rectum, where diagnosis is facilitated by an alarm symptom and where variations in access are lower. Records from the Northern and Yorkshire Cancer Registry from 1994 to 2002 with ICD 10 C77–C80 (CUP, including categories where investigations may have been incomplete or no primary cancer was found) and C20 (malignant neoplasm of rectum) were combined with travel time to services (primary care, secondary and tertiary services) and the Index of Multiple Deprivation. Logistic regression modelled predictors of CUP were compared with C20 and, within CUP, the odds of a histological basis of diagnosis.

Results: The registry classified 7428 patients as C80, 8849 as C77–C79, and 10 804 as C20. Compared with C20, the number of cases of C80 showed a statistically significant increasing trend with increasing travel time to primary care. Risk also increased strongly with age and deprivation. The results for C77–C79 were similar to those for C80, except that the travel time to primary care showed no effect. Considering all CUP alone, histological diagnosis significantly declined with travel time to the nearest hospital. There was no association with gender and the likelihood of histological diagnosis, but a marked decline with age, a downward trend with deprivation, and an increase when the nearest hospital was a cancer centre.

Conclusions: These findings facilitate the understanding of factors associated with the group of patients that includes those with the least effective access to cancer services.

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Key words: Access to health services; cancer diagnosis; cancer of unknown primary; primary care; rectal cancer; socioeconomic deprivation

Introduction

Policy for the management of cancer in the UK has been driven by the observation that at the end of the previous century, survival rates from cancer were worse in the UK than in comparable European countries [1]. The reasons continue to be debated but, following the *NHS Cancer Plan* [2], policies sought to improve the quality of care by increasing specialist recruitment and enhancing services in selected centres. Some specialist diagnostic and therapeutic

services for cancer have been concentrated in selected large hospitals, known as Designated Cancer Centres. Typical district general hospitals, known as Designated Cancer Units, focus on the management of common cancers where high volumes can be sustained.

A possible disadvantage of centralising services in this manner is that populations living further from specialist centres may have difficulties, including gaining transport to provide access to them for treatment, and such difficulties may consequently be associated with poorer disease prognosis [3,4]. Rural general practitioners have complained of the problems of gaining access to treatment for patients living in more remote areas far from cancer treatment centres [5] and a report from the Commission for Rural

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Communities has illustrated some adverse experiences of cancer sufferers and their carers living in rural England, with some patients facing round trips of 100 miles and the topography and quality of local roads further lengthening journey times [6]. There is accumulating evidence that longer travel times have negative effects on access to treatment and the outcome of care for patients with diagnosed cancer [7].

Campbell *et al.* [4] examined the relationship between survival and distance to cancer centres among 64 000 patients diagnosed with common cancers in Scotland between 1991 and 1995. They found that increasing the distance from a cancer centre was associated with less chance of diagnosis before death for stomach, breast and colorectal cancers and poorer survival after diagnosis for prostate and lung cancers. A study of 5147 cases of colorectal cancer in southern England [8] also found that postoperative survival declined with increasing distance from a treatment centre.

Our previous study of cancers of the breast, bowel, lung, prostate and ovary, which used records from the former Northern and Yorkshire Cancer Registry and Information Service (NYCRIS), added to the evidence. We found that survival from cancers of the prostate was adversely associated with travel time to the patient's general practitioner, as was the likelihood of presenting at late stage for breast or colorectal cancer [9]. Access to the centralised services of radiotherapy and thoracic surgery was shown to be reduced with increasing travel time, as was some chemotherapy [10] and the type of surgery used to treat breast cancer was influenced by access to radiotherapy [11]. These analyses were adjusted for deprivation of the area of residence, but more detailed analyses for lung cancer showed that the issues of access were minimal for the least deprived localities and greatest for the most deprived [12]. Similar observations were made for colonic but not rectal cancer; the symptom patterns of these tumours suggest that difficulty in suspecting the diagnosis was key [13]. There was also a tendency for those living furthest from a hospital to be recorded as having been diagnosed on the date of death [14].

Cancer service development since 2000 initially concentrated on hospital services but more recently the focus has shifted to the timing of diagnosis [15]. This requires improvement in the interface between primary care, where general practitioners have to decide if it is appropriate to consider the diagnosis in a patient, and secondary care, where the facilities for investigation are located. For patients with common epithelial cancers, those from deprived areas have been shown to be more likely to have their first hospital admission as an emergency event [16]. Current understanding of the role of primary care in the process is discussed in the Lancet Oncology Commission on the subject [17]. Practitioners in this discipline have a role throughout the cancer patient's journey, but it is especially important leading up to the diagnosis.

There is concern about patients being admitted to hospital with previously undiagnosed cancer. The National Institute for Health and Care Excellence has issued a guideline for the management of patients with malignancy of

unknown primary [18], a decade after the Cancer Plan [2]. That document addresses the fact that this group of patients comprises two distinct entities; those patients whose primary site has not been identified because of presentation with very advanced disease and those in whom a primary cannot be identified. The first entity suggests that timely access to the diagnostic services of the Health Service has not been attained. Here we investigate that process. We decided to approach this entity in the same way and for the same time period over which we had looked at data concerning common cancer sites as an addition to the previous work. Taken as a whole, our body of work provides a detailed picture of the state of services at an important time point.

We hypothesised that cancers of unknown primary (CUPs) would include more patients who faced difficulties in gaining access to health services through residing in deprived areas or through having to travel further to cancer facilities. To test this we compared the diagnosis of CUP with a comparator tumour, carcinoma of the rectum, where associations with access are not strong [13]. Indeed, few patients with rectal cancer require multiple consultations before a diagnosis is reached [19], probably because it has a signature symptom of rectal bleeding. Undiagnosed rectal cancer is therefore unlikely to contribute greatly to the total of CUP patients. The data we have analysed are from the time the Cancer Plan was being introduced and our results therefore form a historically relevant baseline against which the effects of that plan can be measured.

Materials and Methods

Setting

The study drew patients from the area covered by the former NYCRIS, which extended from the Scottish border to the Humber Estuary. The population covered was around 6.7 million. About 17 500 new malignant cancer patients were assessed annually within this region during the period of study, and 5 year survival figures were lower than the national average for the majority of sites [20]. As well as widely distributed primary care services operated by general practitioners, the region contains 32 main acute hospitals (secondary care units) providing diagnostic and basic therapeutic services. Cancer centres (specialist tertiary care units) are located in Hull, Leeds, Middlesbrough and Newcastle. The study area is predominantly rural and, in the counties of Northumberland and Cumbria, contains some of the most remote parts of Great Britain. The populations of some districts in those counties live an average distance of over 35 km from their nearest main acute hospital, compared with a national average distance of under 9 km [2]. The area also includes the urban conurbations of Leeds and Tyneside and other industrial cities, with significant pockets of inner-city deprivation. Among the hospitals that are not cancer centres we have not separately analysed data concerning those that had an in-house oncology service. These include several in West Yorkshire and Carlisle Infirmary, which has a radiotherapy facility.

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