National Bowel Cancer Audit

End of Life Short Report

NBOCA: Short Report

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Executive summary

Patients are defined as approaching the 'end of life' when they are identified as being likely to die within 12 months. Concerns have been raised about the variation in the quality of end of life care received by patients, with several reports highlighting poor care. This short report aimed to look at patients diagnosed with colorectal cancer who were at the 'end of life'.

As expected, patients who did not live for more than a year from diagnosis tended to be older, have metastases, have poorer performance status, and to undergo no surgical procedure.

However, what was not known was that these patients had, on average, two hospital admissions with a length of stay of 18 days each and that a third spent over a month of their last year in hospital.

86% of those who lived for less than one year had at least one emergency hospital admission and, if that admission was in their last month, nearly two thirds died in hospital.

Of concern, patients with higher levels of deprivation appear to be more likely to die within 12 months of diagnosis, despite adjustment for other factors. This suggests that there may be some inequalities in access to colorectal cancer care services.

Introduction

Patients are defined as approaching the 'end of life' when they are identified as being likely to die within 12 months. This encompasses those patients with advanced, progressive, incurable conditions as well as those with acute life-threatening ones.[1]

Concerns have been raised about the variation in the quality of end of life care received by patients, with several reports highlighting poor care. Within England, a national framework 'Ambitions for Palliative and End of Life Care' was initiated in 2015 and presents six ambitions for improved care including individual care, equal access to services and co-ordinated care.[2] In Wales, there is the 'Palliative and End of Life Care Delivery Plan 2017'.[3] There is currently a lack of literature, particularly within the UK, regarding end of life care for colorectal cancer patients.

This short report aims to look at patients diagnosed with colorectal cancer who have not survived beyond one year and therefore by definition at diagnosis are at the 'end of life'. It is important to be able to identify these patients as early as possible in order to involve palliative care services in a timely manner and prevent futile investigations, procedures and hospital admissions. In turn, this should help to improve important aspects of end of life care such as symptom control, communication with patients and their families, and death in the patient's place of choice.

We will establish the proportion of newly diagnosed colorectal cancer patients who do not survive beyond one year after diagnosis, as well as quantifying the number of hospital admissions and total time spent in hospital by these patients. This should highlight the current experiences and the distribution of resources for this group of patients with colorectal cancer. We will also assess patient, tumour and clinical characteristics of patients dying within one year of diagnosis compared to those patients surviving beyond one year, to identify risk factors for death within one year of diagnosis.

Methods

Data from the National Bowel Cancer Audit (NBOCA) for patients newly diagnosed with colorectal cancer in England and Wales between 1st April 2010 and 31st March 2016 was used. Records were linked at patient-level to Hospital Episodes Statistics (HES) and Patient Episode Database Wales (PEDW), administrative databases for NHS hospitals in England and Wales

respectively, and Office of National Statistics (ONS) records to identify date of death. A date of death was available for patients dying before 1st April 2017, providing a minimum of 12 months follow-up.

Patients were identified as dying within 12 months of diagnosis if they had a date of death recorded within 12 months of their recorded date of diagnosis. All analyses defined death as that from all causes including non-cancer deaths. The remaining patients were considered to have survived beyond one year. Data regarding age, sex, IMDQ (Index of Multiple Deprivation Quintile), procedure, urgency (elective/scheduled or urgent/emergency), performance status (World Health Organisation), diagnostic tumour, node and metastasis (TNM) staging and cancer site were obtained from NBOCA. Diagnostic admission type (elective or emergency) and co-morbidities (Royal College of Surgeons' Charlson score) were obtained from linked HES/PEDW records.

For the analysis assessing the proportion of patients dying within 12 months of diagnosis, 177,426 patients were included. This cohort was also used to evaluate hospital use in the last year of life. For the multivariable analysis of factors influencing survival of less than one year, the cohort included patients diagnosed between 1st April 2013 and 31st March 2015. This cohort included 56,631 patients, with 12,572 patients (22%) surviving less than one year. This time period was chosen because data completeness for some data items was substantially improved from 2013.

A multivariable random-effects logistic regression model was fitted to estimate the odds ratio of death within one year of diagnosis, for the following risk factors: age group, IMDQ, diagnostic admission type, urgency index procedure, pre-treatment TNM staging, cancer site, performance status and Charlson co-morbidity score. Sex and year of diagnosis did not improve the fit of the model and were therefore omitted. Missing values for the risk factors were imputed with multiple imputation using chained equations, creating ten data sets and using Rubin's rules to combine to estimated odds ratios across the data sets.[4]

Results

- Approximately, one fifth of patients who are newly diagnosed each year with colorectal cancer will die within a year of their diagnosis, representing a significant number of patients (Table 1, page 4). There has been no improvement in this figure over the 5-year period.

- The strongest risk factors for surviving less than one year beyond diagnosis included old age, poor performance status, no procedures and presence of metastatic disease. Protective factors included less deprivation and the cancer being present in the rectum compared to other parts of the colon. (Table 2, page 5).

For patients surviving less than one year:

- The median number of total overnight admissions was 2 and the total median duration of stay was 18 days (emergency and non-emergency admissions).

- Approximately one third of patients spent a total of more than one month of their last year of life in hospital (emergency and non-emergency admissions).

- The median number of emergency admissions was 2. 86.4% had at least one emergency admission, 52.4% two or more, 28.1% three or more, and 13.9% four or more.

- 47.3% of patients had at least one emergency admission in their last month of life and of these, 62.7% subsequently died in hospital.

- Nearly one fifth of patients had at least one emergency admission in their last week of life and of those, 87.9% subsequently died in hospital.

Summary and conclusions

It is important that clinicians are able to recognise patients who are unlikely to survive beyond one year from diagnosis. This accounts for ~20% of newly diagnosed colorectal cancer patients and constitutes a significant demand on NHS resources. This must be acknowledged and planned for, particularly in the context of an ageing population. Optimisation of the availability and appropriateness of end of life care for colorectal cancer patients is essential, particularly as it is a disease predominant in the elderly.

Ultimately, being able to better predict which patients we do not think will survive beyond 1 year should facilitate earlier palliative care referral and prompt symptom control, avoid unnecessary investigations and treatments, and reduce the number and length of unplanned hospital admissions. Patients should have the choice to die in a preferred place which, for many, is their own homes rather than in hospital. Patients having unplanned admissions in their last weeks of life, appear to be vulnerable for dying in the hospital setting.

This report highlights that, as would be expected, elderly patients, those with a poor performance status and those with metastatic disease at diagnosis are most at risk of dying within one year. However, of concern, there appears to be a protective influence for patients with lower levels of deprivation even after adjustment for other factors including emergency presentation, performance status and cancer stage, suggesting that there may be some inequality in access to colorectal cancer services. Socioeconomic inequalities have previously been demonstrated in colorectal cancer patients.[5] It is important to ensure that patients identified as likely to die within 12 months of diagnosis have access to appropriate community support and palliative care services.

We have carried out additional work looking at place of death in colorectal cancer patients.[6] Similar to this work, deprivation was identified as being a key determinant in place of death, with the most deprived patients more likely to die in hospital compared to the least deprived. Patients dying within 1 year of diagnosis were also most likely to die in hospital. This supports the importance of being able to identify this group of patients so that clinicians can undertake discussions with patients and their families regarding preferred place of death.

Implementing adequate community and palliative care support is crucial in reducing the amount of time that patients are spending in hospital in their last year of life as well as minimising unplanned and unwanted hospital deaths. A few recent studies have suggested that access to community palliative care services are associated with better end of life quality indicators such as avoiding hospital deaths and emergency admissions.[7-8] This report provides the basis for further analyses and research directed at end of life care in colorectal cancer patients.

Table 1 – Proportion of patients newly diagnosed with colorectal cancer who die within 12 months of diagnosis

Audit Year	2011	2012	2013	2014	2015	2016
Total colorectal cancer cases diagnosed	28,382	29,591	30,573	29,868	29,990	29,022
Number of patients dying within 12 months of diagnosis (%)	6,376 (22.5)	6,562 (22.2)	6,917 (22.6)	6,620 (22.2)	6,675 (22.3)	6,031* (20.8)

*Reduced proportion of deaths in 2016 most likely corresponds to time delays in patients recorded as dying within most recent extract from ONS. Work is planned for the 2019 annual report to explore case ascertainment by utilising new linkage to data from the National Cancer Registration and Analysis Service (NCRAS), which has not been carried out to date.

Table 2 – Multivariate analysis for death within 1 year of colorectal cancer diagnosis

	Crude odds ratios (95% confidence interval)	p value	Adjusted odds ratios (95% confidence interval)	p value
Age at diagnosis		**<0.001**		**<0.001**
<50	1.0		1.0	
50-64	0.96 (0.85-1.08)		1.20 (1.03-1.39)	
65-74	1.38 (1.23-1.55)		1.79 (1.55-2.07)	
75-84	2.51 (2.24-2.81)		2.57 (2.22-2.97)	
>85	5.55 (4.94-6.25)		3.34 (2.86-3.90)	
IMD quintile		**0.0129**		**0.0131**
1 (most deprived)	1.0		1.0	
2	0.95 (0.89-1.01)		1.00 (0.92-1.09)	
3	0.85 (0.80-0.91)		0.93 (0.85-1.02)	
4	0.81 (0.76-0.87)		0.93 (0.85-1.01)	
5 (least deprived)	0.77 (0.72-0.82)		0.88 (0.80-0.96)	
RCS Charlson score		**<0.001**		**<0.001**
0	1.0		1.0	
1	1.65 (1.58-1.74)		1.21 (1.13-1.29)	
2+	2.58 (2.44-2.74)		1.34 (1.24-1.46)	
Performance status		**<0.001**		**<0.001**
0	1.0		1.0	
1	2.15 (2.01-2.31)		1.40 (1.28-1.52)	
2	5.44 (5.01-5.90)		2.52 (2.29-2.79)	
3+	16.54 (15.25-17.94)		4.49 (4.00-5.04)	
Diagnostic admission		**<0.001**		**<0.001**
Elective	1.0		1.0	
Emergency	5.65 (5.40-5.90)		2.31 (2.16-2.47)	
Procedure		**<0.001**		**<0.001**
Elective	1.0		1.0	
Emergency	5.47 (5.13-5.84)		1.53 (1.41-1.67)	
No procedure	14.66 (13.92-15.44)		4.56 (4.27-4.88)	
Cancer site		**<0.001**		**<0.001**
Ascending colon	1.0		1.0	
Caecum	1.22 (1.13-1.32)		0.99 (0.90-1.10)	
Hepatic flexure	0.84 (0.75-0.93)		1.13 (0.97-1.31)	
Transverse colon	1.23 (1.12-1.35)		1.10 (0.97-1.25)	
Splenic flexure	1.23 (1.08-1.40)		1.10 (0.93-1.30)	
Descending colon	0.94 (0.83-1.06)		0.92 (0.78-1.07)	
Sigmoid	0.77 (0.71-0.83)		0.81 (0.73-0.89)	
Rectosigmoid	0.84 (0.75-0.93)		0.88 (0.77-1.01)	
Rectal	0.62 (0.58-0.67)		0.70 (0.64-0.77)	
T-stage diagnosis*		**<0.001**		**<0.001**
T0-T1	1.0		1.0	
T2	2.12 (1.78-2.51)		1.17 (0.95-1.44)	
T3	4.60 (3.95-5.36)		1.56 (1.30-1.87)	
T4	12.98 (11.11-15.17)		2.92 (2.43-3.52)	
N-stage diagnosis*		**<0.001**		**<0.001**
N0	1.0		1.0	
N1	1.97 (1.87-2.08)		1.14 (1.06-1.22)	
N2	3.54 (3.34-3.76)		1.77 (1.62-1.93)	
M-stage diagnosis*		**<0.001**		**<0.001**
M0	1.0		1.0	
M1	8.77 (8.37-9.19)		4.15 (3.89-4.42)	

*T-stage relates to how deeply the tumour has grown through the wall of the bowel, with increasing depth from T0-T4. N-stage relates to whether the cancer has spread to lymph nodes. N0 means that no lymph nodes are involved; N1 involves local lymph nodes and N2 distant lymph nodes. M-stage relates to whether the cancer has spread other parts of the body. M0 means the cancer has not spread and M1 means it has spread.

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