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Death from cancer: frequent unscheduled care

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ABSTRACT

Objective To examine the demographic, clinical, and temporal factors associated with cancer decedents being a frequent or very frequent unscheduled care (GP-general practice Out-Of-Hours (GPOOH) and Accident & Emergency (A&E)) attender, in their last year of life.

Methods Retrospective cohort study, of all 2443 cancer decedents in Tayside, Scotland, over 30- months period up to 06/2015, comparing frequent attenders (5–9 attendances/year) and very frequent attenders (≥ 10 attendances/year) to infrequent attenders (1–4 attendances/year) and non-attenders. Clinical and demographic datasets were linked to routinely-collected clinical data using the Community Health Index number. Anonymised linked data were analysed in SafeHaven, using binary/multinomial logistic regression, and Generalised Estimating Equations analysis.

Results Frequent attenders were more likely to be older, and have upper gastrointestinal (GI), haematological, breast and ovarian malignancies, and less likely to live in accessible areas or have a late cancer diagnosis. They were more likely to use GPOOH than A&E, less likely to have face-to-face unscheduled care attendances, and less likely to be admitted to hospital following unscheduled care attendance.

Conclusions Age, cancer type, accessibility and timing of diagnosis relative to death were associated with increased likelihood of being a frequent or very frequent attender at unscheduled care.

Key messages

What was already known?

- Emerging evidence suggests unscheduled care attendance by cancer decedents is more common than previously believed.
- Few previous studies have examined patient-level or attendance-level factors associated with cancer decedents' risk of being a frequent or very frequent unscheduled care attender.

What are the new findings?

- Frequent attenders were more likely to be older and to have upper gastrointestinal, haematological, breast and/or ovarian malignancies than infrequent attenders.
- Frequent and very frequent attenders were more likely to use general practice out of hours than accident and emergency, less likely to have face-to-face attendances and less likely to be admitted to hospital, than infrequent attenders.

What is their significance?

Clinical

- Identifying risk factors associated with frequent unscheduled care attendance allows for policy and practice interventions for minimising avoidable unscheduled care use to be targeted towards those for who would derive the greatest benefit.

Research

- Integration of such risk factors into individual risk predictor tools would facilitate early identification of cancer decedents at high risk of becoming frequent unscheduled care attenders.

INTRODUCTION

Use of unscheduled care by people who die from cancer ('cancer decedents') is increasing; fueled by rising unscheduled care use in the general population and an increase in the total number of people dying from cancer in the UK.^{1,2} 'Unscheduled care' is any healthcare accessed by the public without prior arrangement³; in the UK, it is predominantly delivered by general practice out-of-hours (GPOOH) or accident and emergency (A&E)

departments. Unscheduled care is designed to address acute, episodic medical needs; it is among the most pressurised parts of the healthcare system. Due to the nature of unscheduled care delivery, patients are often in unfamiliar settings, being cared for by clinicians they do not know and who do not know them or their medical history, at antisocial times of day or night, and without the social or care support that they might choose to access for predictable or planned care. The combination of



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these factors can make accessing unscheduled care a distressing experience that can disrupt previous treatment plans, and lead to unwanted outcomes, including undesired hospital admissions.^{4,5}

While most patients with cancer use unscheduled care infrequently,^{4,5} some become frequent or very frequent attenders. Identifying risk factors for frequent unscheduled care use would enable the targeting of resources to support people with advanced cancer with higher levels of modifiable and non-modifiable risk factors for frequent unscheduled care use, to anticipate, and therefore minimise, avoidable unscheduled care use.

This study aimed to identify demographic, temporal and clinical factors associated with being a frequent or very frequent unscheduled care attender in a population of people who die from cancer.

METHODS

This retrospective cohort study examined 2443 cancer decedents in Tayside, Scotland, over a 30-month period up to 2015. For the purposes of this study, the term ‘cancer decedents’ refers to people who went on to die from cancer. Having died from cancer was defined as having ‘cancer’ (Ddefined in the ICD-10 : International Statistical Classification of Diseases and Related Health Problems) in position 1 of the death certificate registered with the General Register Office. Data linkage was effected through use of the Community Health Index number, which is a unique single patient identifier, used throughout all healthcare contacts in National Health Service (NHS) Scotland, and attached to all healthcare data. Demographic data were linked to patient data from the Cancer Registry, Scottish Executive Urban Rural Classification and Scottish Index of Multiple Deprivation, and matched to routinely collected clinical data from all unscheduled care contacts. The SafeHaven platform was used to anonymise, store and analyse data securely.

Chi-squared and binomial logistic regression were used for patient-level analysis, and multinomial logistic regression and Generalised Estimating Equations analysis was used for attendance-level analysis to account for correlation between repeated measures (multiple attendances by a single person). Analysis deployed SPSS V.25 (online supplemental appendix 1).

There is no universally agreed definition of ‘frequent’ attenders; definitions range from 3 to 10 attendances per person per year.^{6–9} We defined infrequent attenders as those with one to four attendances/year; frequent attenders had five to nine attendances/year and very frequent attenders had ≥ 10 attendances/year.

RESULTS

In the last year of life, one in five cancer decedents in this cohort were either frequent (n=406, 16.6%) or very frequent (n=108, 4.4%) unscheduled care attenders. Attendances by frequent or very frequent

unscheduled care users represented more than half (n=3986 attendances, 57.7%) of the cohort’s total attendances. The majority of these appointments were in GPOOH (n=3477, 87.2%) compared with A&E (n=509 12.8%).

Patient-level factors significantly associated with being a frequent or very frequent attender included: age, cancer type, rurality, deprivation and timing of diagnosis. On multivariate analysis, cancer decedents who were frequent attenders were likely to be older, were less likely to have upper gastrointestinal (GI), haematological or breast or ovarian malignancies, less likely to live in accessible areas, and less likely to have a late cancer diagnosis, compared with non-attenders (table 1). (Table 1 presents an abbreviated analysis which contains only factors found to be significant on univariate or multivariate analysis. For full details of all factors, including those that did not meet the threshold for significance, please see the online supplemental table S1.)

Attendance-level factors significantly associated with being a frequent or very frequent attender include: clinical priority, attendance type, outcome from attendance and type of unscheduled care (table 1). While on univariate analysis ‘presenting complaint’ showed a significant association with higher attendance frequency, this association disappeared once corrected for correlation with other clinical factors on multivariate analysis. Frequent or very frequent attenders had higher odds of having attendances with higher clinical priority categories than infrequent attenders. On both univariate and multivariate analysis, attendance type, outcome from attendance and unscheduled care type were significantly associated with being a frequent or very frequent attender compared with infrequent attenders. Frequent and very frequent attenders were less likely to have attended A&E than GPOOH (table 1), and were more likely to have had remote assessments (including NHS24 advice) than face-to-face attendances. Frequent and very frequent attenders were less likely to be admitted to hospital following unscheduled care contact, and were less likely to have follow-up arranged after their attendance, compared with infrequent attenders.

DISCUSSION

What was already known?

Previous studies suggest that frequent attenders account for 1%–5% of unscheduled care attendances^{9–12}; this study suggests that previous research significantly underestimates the magnitude of frequent attendance among cancer decedents.

Our finding that gender was not associated with unscheduled care attendance frequency diverged from findings in other studies.^{13,14} The association between older age and higher attendance frequency was found in one previous study,¹⁴ but disputed by another.⁵ The association between living in accessible areas and

Table 1 Patient and attendance level factors associated with cancer decedents being a frequent or very frequent unscheduled care attender

Patient level analysis: (reference category = non-attenders (n=539 cancer decedents))

Patient level factors		Patients (n) (%)	Univariate: unadjusted OR (95% CI)	p value (adj)	Multivariate: adjusted OR
Frequent attenders					
Age					
(5–9 attendances per year)	<65	73 (18.0)	0.61 (0.40 to 0.92)	0.001	0.48 (0.31 to 0.74)
(n=406 cancer decedents)	65–74	103 (25.4)	0.61 (0.42 to 0.89)	0.002	0.54 (0.36 to 0.80)
	75–84	133 (32.8)	0.73 (0.51 to 1.06)	0.05	0.68 (0.47 to 1.00)
	≥85 (ref)	97 (23.9)	1	.	1
Cancer type					
	Lung	112 (27.6)	0.76 (0.50 to 1.15)	0.16	0.74 (0.48 to 1.13)
	Upper GI	84 (20.7)	0.64 (0.42 to 0.98)	0.02	0.60 (0.38 to 0.93)
	Bowel	58 (14.3)	0.96 (0.59 to 1.56)	0.55	0.86 (0.52 to 1.43)
	Breast; ovarian	37 (9.1)	0.64 (0.38 to 1.09)	0.02	0.51 (0.29 to 0.90)
	Prostate	19 (4.7)	1.03 (0.50 to 2.12)	0.74	0.88 (0.41 to 1.88)
	Haematological	25 (6.2)	0.37 (0.21 to 0.66)	0.001	0.36 (0.20 to 0.64)
	Other (ref)	71 (17.5)	1	.	1
Rurality grouped					
	Urban	270 (67.8)	0.76 (0.49 to 1.18)	0.44	0.83 (0.52 to 1.33)
	Accessible	79 (19.8)	0.43 (0.26 to 0.70)	0.001	0.43 (0.26 to 0.71)
	Remote (ref)	49 (12.3)	1	.	1
Deprivation					
	SIMDS 1	78 (19.6)	1.76 (1.12 to 2.77)	0.04	1.64 (1.02 to 2.62)
	SIMDS 2	55 (13.8)	1.51 (0.93 to 2.44)	0.21	1.38 (0.84 to 2.27)
	SIMDS 3	79 (19.8)	1.42 (0.92 to 2.21)	0.06	1.53 (0.98 to 2.40)
	SIMDS 4	133 (33.4)	1.61 (1.07 to 2.40)	0.007	1.79 (1.18 to 2.72)
	SIMDS 5 (ref)	53 (13.3)	1	.	1
Time between diagnosis and death					
	0–12 weeks before death	108 (26.6)	0.60 (0.43 to 0.83)	0.001	0.54 (0.38 to 0.77)
	13–25 weeks before death	63 (15.5)	1.16 (0.77 to 1.75)	0.74	1.08 (0.70 to 1.67)
	26–38 weeks before death	56 (13.8)	1.64 (1.04 to 2.61)	0.04	1.67 (1.03 to 2.70)
	39–51 weeks before death	46 (11.3)	1.32 (0.82 to 2.12)	0.19	1.39 (0.85 to 2.28)
	≥52 weeks before death	133 (32.8)	1	.	1
Very frequent attenders					
(≥10 attendances per year)					
Time between diagnosis and death					
(n=108 cancer decedents)	0–12 weeks before death	24 (22.2)	0.47 (0.27 to 0.81)	0.02	0.48 (0.27 to 0.87)
	13–25 weeks before death	16 (14.8)	1.03 (0.54 to 1.97)	0.82	1.08 (0.55 to 2.13)
	26–38 weeks before death	16 (14.8)	1.64 (0.54 to 1.97)	0.11	1.78 (0.89 to 3.57)
	39–51 weeks before death	14 (13.0)	1.41 (0.70 to 2.83)	0.21	1.58 (0.77 to 3.23)
	≥52 weeks before death	38 (35.2)	1	.	1

Attendance level analysis: (reference category = attendances by infrequent attenders (n=2928 unscheduled care attendances))

Attendances by all cancer decedents	Attendance level factors	All cancer decedents (n=6914 attendances) (%)	Infrequent attenders (n=2928 attendances) (%)	Frequent and very frequent attenders (n=3986 attendances) (%)	Univariate: unadjusted Wald OR (95% CI)	Wald p value (adj)	Multivariate: adjusted Wald OR (95% CI)
Attendances by all cancer decedents							
Type of unscheduled care							
(n=6,914 unscheduled care attendances in the last year of life)	A&E	1463 (21.2)	656 (22.4)	509 (12.8)	0.51 (0.45 to 0.58)	<0.001	0.69 (0.59 to 0.82)
	GPOOH (ref)	5451 (78.8)	2272 (77.6)	3477 (87.2)	1	–	1
Presenting complaint							
	Pain	818 (11.8)	388 (13.3)	430 (10.8)	0.71 (0.61 to 0.83)	0.54	1.06 (0.89 to 1.25)
	Unwell and palliative care	1325 (19.2)	563 (19.2)	762 (19.1)	0.87 (0.77 to 0.99)	0.91	1.01 (0.88 to 1.16)
	Breathlessness	248 (3.6)	120 (4.1)	128 (3.2)	0.69 (0.53 to 0.89)	0.35	1.16 (0.87 to 1.53)
	GI symptoms	358 (5.2)	165 (5.6)	193 (4.8)	0.75 (0.61 to 0.94)	0.59	0.94 (0.75 to 1.18)
	Infection	591 (8.5)	248 (8.5)	343 (8.6)	0.89 (0.75 to 1.06)	0.28	1.11 (0.92 to 1.34)

Continued

Table 1 Continued

Attendance level analysis: (reference category = attendances by infrequent attenders (n=2928 unscheduled care attendances))

Attendances by all cancer decedents	Attendance level factors	All cancer decedents (n=6914 attendances) (%)	Infrequent attenders (n=2928 attendances) (%)	Frequent and very frequent attenders (n=3986 attendances) (%)	Univariate: unadjusted Wald OR (95% CI)	Wald p value (adj)	Multivariate: adjusted Wald OR (95% CI)
	Acute neurological Symp.	214 (3.1)	128 (4.4)	86 (2.2)	0.43 (0.33 to 0.57)	0.1	0.77 (0.57 to 1.05)
	Missing or other (ref)	3360 (48.6)	1316 (44.9)	2044 (51.3)	1	–	1
	Clinical priority						
	Highest clinical priority*	569 (8.2)	263 (9.0)	306 (7.7)	0.86 (0.72 to 1.03)	0.04	1.23 (1.01 to 1.50)
	Middle clinical priority	2467 (35.7)	1015 (34.7)	1452 (36.4)	1.06 (0.96 to 1.17)	<0.001	1.31 (1.17 to 1.46)
	Lowest clinical priority (ref)	3878 (56.1)	1650 (56.4)	2228 (55.9)	1	–	1
	Attendance type						
	GP visit or ambulance	3724 (53.9)	1715 (58.6)	2009 (50.4)	0.61 (0.55 to 0.68)	0.002	0.81 (0.71 to 0.93)
	In-person attendance	721 (10.4)	370 (12.6)	351 (8.8)	0.49 (0.41 to 0.58)	<0.001	0.69 (0.56 to 0.84)
	Other (ref)	2469 (35.7)	843 (28.8)	1626 (40.8)	1	–	1
	Outcomes of attendance						
	GP follow-up	2315 (33.5)	1019 (34.8)	2315 (33.5)	0.76 (0.67 to 0.86)	<0.001	0.75 (0.66 to 0.86)
	Admitted to hospital	1408 (20.4)	773 (26.4)	1408 (20.4)	0.49 (0.42 to 0.56)	<0.001	0.55 (0.46 to 0.65)
	Passed to another clinician	193 (2.8)	78 (2.7)	193 (2.8)	0.88 (0.65 to 1.19)	0.98	1.01 (0.74 to 1.37)
	Missing or other	1260 (18.2)	410 (14.0)	1260 (18.2)	1.23 (1.06 to 1.44)	0.55	1.05 (0.89 to 1.25)
	No follow-up (ref)	1738 (25.1)	648 (22.1)	1738 (25.1)	1	–	1

Rurality: 'Urban' comprises SEUR1&2, 'Accessible' comprises SEUR3&5 and 'Remote' comprises SEUR 4 & 6. 33 people had missing data. Deprivation: Scottish Index of Multiple Deprivation (SIMD). Category 1 is most deprived, and category 5 is least deprived. Missing data: 33 people in the cohort had missing SEUR and SIMD data and were omitted from the rurality and deprivation section of the regression analysis.

*Highest clinical priority: GPOOH 'emergency'; A&E 'resuscitation'. Middle clinical priority: GPOOH 'urgent' and A&E 'majors'. Lowest clinical priority: GPOOH 'routine' and A&E 'minors'.

A&E, accident and emergency; GI, gastrointestinal; GPOOH, general practice out of hours; SEUR, Scottish Executive Urban Rural Classification; SIMD, Scottish Index of Multiple Deprivation.

reduced likelihood of being a frequent or very frequent attenders was consistent with a previous study,¹² as was the association between some cancer types (upper GI, haematological, breast or ovarian malignancies) and having reduced odds of being a frequent attender.^{12 13} The reduced likelihood of hospital admission after each attendance by frequent attenders was consistent with another study¹⁵; outcomes other than admission have not been previously studied.⁴

What are the new findings?

This research suggests that the proportion of cancer decedents who are frequent or very frequent unscheduled care attender is substantially greater than previously believed, and that this group accounts for over half of all unscheduled care attendances by cancer decedents.

In patient-level factors, this research found that frequent and very frequent attenders had lower odds of having a late cancer diagnosis, compared with infrequent attenders; associations between attendance frequency and timing of cancer diagnosis have not been hitherto identified.⁴ This may be caused by people who are frequent attenders having more contact

opportunities with healthcare in which a diagnosis could be made and therefore being diagnosed sooner, or it could be that having a known cancer diagnosis changes a patient's illness behaviour and causes them to present to unscheduled care for symptoms they might not otherwise have sought medical attention for.

In attendance-level analysis, this research demonstrated, for the first time, an association between being a frequent or very frequent attender and unscheduled care type, clinical priority and consultation type, as well as demonstrating no significant association with presenting complaint.

Our novel finding that frequent and very frequent attenders were more likely to attend GPOOH than A&E suggests that interventions aimed at reducing avoidable unscheduled care use should be implemented in GPOOH, rather than A&E. The link between having a high clinical priority and increased attendance frequency found in this study is consistent with previous work,¹⁴ though apparently at odds with lower chances of hospital admission following unscheduled care attendance experienced by frequent attenders. Particularly relevant, given the COVID-19-induced

move towards remote consultations, was our finding that frequent and very frequent attenders were more likely to have had remote consultations than face-to-face consultations. This association between attendance frequency and remote consultations has not been demonstrated in the previous literature. It suggests that consulting in a remote capacity may be less effective at managing clinical problems, reassuring patients, or addressing clinical needs, and that the remote nature of prior consultations may in fact be driving the need to represent in future. This is particularly relevant with regard to representations, as, frequent and very frequent attenders were less likely to have follow-up care arranged after their unscheduled care attendance, compared with infrequent attenders.

Previous studies, which relied largely on univariate analysis, had found that presenting complaint was associated with attendance frequency. However, this research found no significant association between cancer decedents' presenting complaint and their attendance frequency, when corrected for associations with other clinical factors, particularly clinical priority. Identifying a lack of association between presenting complaint and attendance frequency suggests that many existing policy and practice interventions which are aimed at addressing symptoms may be misdirected and not yielding the desired impact. Resources and support may be better deployed to address modifiable risk factors or supporting patients' higher levels of non-modifiable risk factors for unscheduled care use. It should, however, be noted that information on presenting complaint was obtained through the coded 'reason for attendance' recorded during consultations, and that this may not have always been complete or accurate. The association between presenting complaint and attendance frequency may therefore be more complicated than appears from coded data alone. Further analysis, including qualitative studies or free text analysis of consultations, is needed in order to fully characterise any potential associations between clinical reason for attendance and attendance frequency.

What is their significance?

Clinical

Identifying cancer decedents who are at high risk of becoming frequent unscheduled care attenders would allow clinicians to deliver targeted anticipatory support to ensure maximum impact. Policy and practice interventions should focus on addressing modifiable risk factors for frequent attendance, and on supporting people with non-modifiable risk factors, including age and cancer type. These interventions may include improved in-hours anticipatory care planning and provision of 'just in case' medication, additional community support around times of diagnosis and death, and streamlined out-of-hours care pathways for cancer patients. Given the association between

frequent attendance and remote consultations, interventions aimed at minimising avoidable unscheduled care use among cancer decedents may need to avoid remote consultations in order to have maximum effect.

Research

The risk factors identified in this research could be used to generate personal risk prediction scores that could serve to identify patients who have a high risk of unscheduled care attendance. Such application of risk factors to precision medicine tools would allow clinicians and policymakers to direct resources to the highest-risk individuals, rather than simply to the highest-risk 'risk factors', and would allow for maximum impact. Further research is needed to determine the nature of the impact of remote consultation on attendance frequency, both with respect to cancer decedents and with respect to unscheduled care use in general.

CONCLUSIONS

Frequent and very frequent unscheduled care attenders are more common among cancer decedents than previously thought. Multiple modifiable and non-modifiable demographic and clinical risk factors are associated with increased unscheduled care attendance frequency.

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