The Determinants of Dying Where We Choose: An Analysis of Coordinate My Care

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Word Count: 699 (max 700 permitted)

BACKGROUND (Words: 124)

Enabling individuals to die where they choose is considered a key indicator of quality in end-of-life care.(1) A majority of individuals declare that they would prefer to die at home or in a hospice.(2) In spite of this, a greater proportion of deaths in England occur in a hospital than in a home or hospice setting (48% vs 29%).(3)

Initially developed as the Electronic Palliative Care Co-ordination System for London, England, Coordinate My Care (CMC) enables individuals to create a digital urgent care plan with their clinicians. The service is accessible to all healthcare and social care professionals involved in a patient's care. CMC is a unique dataset that enables analysis of how prospective patient wishes and documented advanced care plans influence end-of-life care.

OBJECTIVES (Words: 26)

To analyse the determinants of achieving preferred place of death to derive clinically relevant approaches associated with an increased proportion of individuals having their wishes realised.

METHODS AND FINDINGS (Words: 357)

We included all individuals aged over 18 with a CMC plan and a recorded place of death who died between 1st March 2011 and 31st September 2016. We built on the theoretical framework of Gomes and Higginson(4) to create a multivariable logistic regression model including age, sex, diagnosis (cancer / non-cancer), World Health Organisation performance score (divided as 0-1, 2, 3, and 4), resuscitation status, first choice preferred place of death

and preferred place of care, to identify mutually-adjusted factors associated with patients achieving their preferred place of death. Patients without a "do not attempt resuscitation" order were considered "for resuscitation" since resuscitation will usually be commenced if needed unless a valid do not resuscitate order is present. Missing covariate data were addressed through multiple imputation. All analyses were performed using Stata version 14 (StataCorp, USA). This study was approved as a service evaluation by the Royal Marsden Hospital Committee for Clinical Research; CMC is hosted by the Royal Marsden Hospital. There was no specific funding for this study.

We analysed 9,027 patients, of whom 77.5% died in their chosen location. A significant majority (8,828/9,027; 97.8%) preferred to die in the non-acute sector, defined as at home, a care home or a hospice (Table 1). When choosing a first preference of place to die, 73.8% (3,660/4,958) of those choosing home, 89.7% (2,623/2,923) a care home, and 67.6% (640/947) a hospice achieved it. 92.6% (2,706/2,923) of those who preferred to die in a care home were usually resident in a care home. Over half (1,122/2,028; 55.3%) of those who did not achieve their preferred place of death died in hospital compared with only 2.1% (144/6,999) of those who died in their preferred location (Table 1).

Individuals who died in their chosen location tended to be female sex, have a poor performance status, and a diagnosis of cancer (Table 1). Clear limits to treatment were associated with achieving preferred place of death. Those with a recorded do not resuscitate order were 76% more likely to die in a place of their choosing than those who were recorded as for resuscitation (OR 1.76, 95% CI 1.56 to 2.00; Table 1).

DISCUSSION (Words: 192)

In this analysis of routinely-collected electronic health records of over 9,000 patients with CMC plans, more than three-quarters of patients died in their preferred place. Almost all patients (97.8%) preferred to be cared for and die outside of hospital. We show that advance care planning in the form of a recorded not for resuscitation status is associated with a 76% greater chance of achieving preferred place of death. Given the evidence of poor prognosis after resuscitation in those with advanced incurable disease,(5) our results suggest that these conversations can be considered a positive gateway to achieving a patient's wishes for their future care.

There are some limitations to these data. Although CMC is the largest digital urgent care planning service in the UK, it is not mandatory. Therefore, it is possible that there is undetermined bias regarding the patients entered and the healthcare professionals creating the records. As CMC is currently London-based, our results may not be applicable in other settings. Further research is needed to explore how best to improve the proportion of individuals who have advance care planning discussions with their clinicians and to overcome perceived barriers to these conversations.

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Table 1: Patient Characteristics and Preferences

	All patients	Patients Not Achieving PPD	Patients Achieving PPD	Adjusted Odds Ratio[a]	P value
	n = 9,027	n = 2,028	n = 6,999		
	Freq. (%) unless otherwise stated				
Age					
Median (25th percentile, 75th percentile)	83 (73,90)	81 (71,88)	84 (74,91)	1.00 (1.00 - 1.00)	0.902
Missing	228 (3)	30 (2)	198 (3)		
Sex					
Male	3,991 (44)	990 (49)	3,001 (43)	1.00	
Female	5,021 (56)	1,033 (51)	3,988 (57)	1.11 (1.00 - 1.24)	0.048
Missing	15 (0.2)	5 (0.3)	10 (0.1)		
Diagnosis					
Other	3,369 (43)	610 (35)	2,759 (45)	1.00	
Cancer	4,544 (57)	1,147 (65)	3,397 (55)	1.26 (1.10 - 1.44)	0.001
Missing	1,114 (12)	271 (13)	843 (12)		
WHO Performance Status					
0-1	176 (2)	68 (4)	108 (2)	1.00	
2	631 (8)	246 (14)	385 (6)	0.97 (0.68 - 1.38)	0.872
3	2,134 (27)	669 (38)	1,465 (24)	1.10 (0.79 - 1.53)	0.579
4	4,871 (62)	766 (44)	4,105 (68)	2.31 (1.65 - 3.23)	<0.001
Missing	1,215 (14)	279 (14)	936 (13)		
Resuscitation Status					
For Resuscitation	1,825 (20)	666 (33)	1,159 (17)	1.00	
Not for Resuscitation	7,202 (80)	1,362 (67)	5,840 (83)	1.76 (1.56 - 2.00)	<0.001
Missing	0	0	0		
Usual Residence Care Home					
Residential / Nursing Home	2,972 (33)	402 (20)	2,570 (37)	[b]	[b]
Missing	0	0	0		
Place of death					
Home	3,484 (39)	181 (9)	3,303 (47)	-	-
Hospital	1,266 (14)	1,122 (55)	144 (2)	-	-
Hospice	1,386 (15)	472 (23)	914 (13)	-	-
Care home	2,852 (32)	219 (11)	2,633 (38)	-	-
Other	39 (0.4)	34 (2)	5 (0.1)	-	-
Missing	0	0	0		
Preferred place of death (First Choice)					
Home	4,958 (55)	1,298 (64)	3,660 (52)	1.00	
Hospital	88 (1)	21 (1)	67 (1)	1.49 (0.85 - 2.63)	0.167
Hospice	947 (10)	307 (15)	640 (9)	0.82 (0.69 - 0.97)	0.018
Care home	2,923 (32)	300 (15)	2,623 (37)	4.50 (2.67 - 7.59)	<0.001
Other	111 (1)	102 (5)	9 (0.1)	0.01 (0.00 - 0.04)	<0.001
Missing	0	0	0		
Preferred place of death (Second Choice)					
Home	762 (25)	153 (30)	609 (24)	[c]	[c]
Hospital	219 (7)	25 (5)	194 (8)	[c]	[c]
Hospice	1,484 (48)	256 (49)	1,228 (48)	[c]	[c]
Care home	560 (18)	61 (12)	499 (20)	[c]	[c]
Other	43 (1)	24 (5)	19 (1)	[c]	[c]
Missing	5959 (66)	1509 (74)	4450 (64)		
Preferred place of care					
Home	5,783 (65)	1,595 (79)	4,188 (60)	1.00	
Hospital	74 (1)	23 (1)	51 (1)	0.85 (0.48 - 1.52)	0.589
Hospice	164 (2)	35 (2)	129 (2)	1.84 (1.21 - 2.79)	0.004
Care home	2,881 (32)	318 (16)	2,563 (37)	0.59 (0.35 - 1.00)	0.050
Other	62 (1)	43 (2)	19 (0.3)	4.81 (1.34 - 17.33)	0.016

	Missing	63 (1)	14 (1)	49 (1)

[a] Adjusted Odds Ratios with 95% Confidence Intervals Showing the Association of Each Variable with Achieving Preferred Place of Death. For each category, odds ratios are compared with their respective base level, displayed as the first of each category and indicated by an odds ratio of 1.00.

[b] We found significant collinearity between usual residence and preferred place of death; usual residence was consequently dropped from the final multivariable logistic regression model.

[c] The proportion of missing data in the second choice preferred place of death variable was considered unacceptably high for its inclusion in the model.