Deprivation is associated with hospital conveyance among patients who are terminally ill.

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Abstract

Background

Hospital admissions of patients who are terminally ill can be associated with poor experiences and unwanted outcomes, such as dying away from home. While area deprivation is associated with emergency hospital admissions in the last year of life, few studies have looked at the relationship between deprivation and ambulance clinicians' decisions to convey a patient to hospital. The aims of this study are to understand overall proportion of terminally ill patients conveyed to hospital by paramedics in North West England, and associations between conveyance and area deprivation.

Methods

This is an observational study using routinely collected ambulance data held by North West Ambulance Service (NWAS) NHS Trust in England, UK. Data on adult (18+) patients coded by ambulance personnel as having a terminal illness were extracted for March 2021 – February 2022. Logistic regression mixed models were used to examine associations between conveyance to hospital and area deprivation. To control for confounding, additional data were collected on age, gender, ethnicity, location, codes related to clinical assessment, and place of residence.

Results

The number of calls attended by ambulance clinicians for terminally ill patients included in the analysis was 1737. Ten percent of calls resulted in the patient being taken to hospital. The odds of being taken to hospital were 1.51 (95% CIs 1.06 – 2.16) greater for patients living in the 20% most deprived areas compared to patients in other areas in the final model, adjusted for age, gender, place of residence, and initial coded reason for the call.

Conclusion

This study suggests patients with terminally illnesses living in the most deprived areas are more likely to be taken to hospital by ambulance clinicians, compared to those in less deprived areas. Overall, however, a small proportion of patients classed as terminally ill in all areas were taken to hospital. This implies that most end-of-life care provided by ambulance clinicians in this region will be in a patient's place of residence, with implications for time, resources, and training.

What is already known on this topic

People living in more deprived areas who have a terminal illness are more likely to experience unplanned hospital admissions than those in less deprived areas. Ambulance clinicians have an important role to play in deciding whether to convey patients to hospital. Few studies have looked at the association between area deprivation and whether patients who are terminally ill are taken to hospital by ambulance services.

What this study adds

The majority of calls to ambulance services in North West England concerning patients with terminal illnesses did not result in the patient being transferred to hospital. Ambulance clinicians were more likely to convey patients with terminal illnesses living in the most deprived areas to hospital, compared to patients in less deprived areas.

How this study might affect research, practice, or policy

Low levels of conveyance of patients who are terminally ill in North West England warrants further investigation in practice and in research to uncover the possible reasons for this pattern. This research highlights the importance of good end of life care skills among ambulance clinicians. End of life care policy should acknowledge the role of ambulance services in helping to deliver this care and consider ways mitigate any socioeconomic inequities in hospital conveyance.

Introduction

People living in more deprived areas are more likely to attend an emergency department (ED) department and to have unplanned or potentially preventable hospital admissions [1-2]. Many patients attending hospital are conveyed there by paramedics responding to an emergency call. Some studies have investigated the relationship between hospital conveyance and social deprivation for specific patient groups, finding greater social deprivation is associated with higher conveyance of care home patients [3]. Few studies have explored the relationship between hospital conveyance and social deprivation for those patients who are terminally ill.

Most people who have a terminal condition prefer to be cared for at home, which for many is also their preferred place of death [4]. However, sudden deterioration of symptoms and uncertainty about what to expect may result in patients and their carers seeking urgent care, including from emergency services. In the UK in 2021, 7.1% of people experienced three or more emergency admissions in the last three months of life, rising to 9.2% for those aged under 75 [5]. For some, an emergency admission to hospital may be appropriate. For many others, however, an emergency hospital admission can be associated with poor experiences and unwanted outcomes, including dying in hospital instead of home [6, 7]. A busy ED environment, where staff may be unable to practice end-of-life skills, can make communication and management of painful symptoms difficult [6]. It is important that patients at the end of life are only transferred to hospital if it is appropriate. Patients who are socioeconomically disadvantaged are at higher risk of emergency department attendance in the last month of life [8]. Poorer health, household factors and poorer access to primary or community care may contribute to why people experiencing socioeconomic hardship, and others, seek support from emergency services [9,10].

There are challenges identifying palliative care patients in ambulance services data. In early 2021, the North West Ambulance Service (NWAS) covering England and part of Wales rolled out a new ‘terminal illness’ impression code. The impression code is inputted by the attending paramedics following the end of an incident to classify the underlying reason for the contact with emergency services. The ‘terminal illness’ code is likely used by paramedics for patients whom they recognise are in the last weeks or days of life. This recognition may follow discussions with family, or if there are indications the patient is receiving support from palliative care services, for example having an Advance Care Plan in place. However, the palliative care population identified using this code may be overestimated or underestimated. Many patients – such as those who have a longer prognosis and are not actively dying - may not have this need recognised by professionals or family caregivers.

Despite limitations, the introduction of this code offers an opportunity to initially examine socioeconomic group differences in hospital conveyance of patients recognised as having a terminal illness by paramedics.

The aims of this study are to use routine data to explore the relationships between hospital conveyance and social deprivation among patients assessed as having a terminal illness by attending ambulance clinicians (paramedics and emergency medical technicians). We will identify the overall proportion conveyed to hospital before examining associations between hospital conveyance and area deprivation. It is hypothesised that worsening deprivation will be associated with higher transfer rates, controlling for age.

Method

This retrospective analysis of a routine dataset from the North West Ambulance Service NHS Trust utilised data collected between 1st March 2021 and 28th February 2022 (the time period for which comparable data were available). The study was approved by the Faculty of Health and Medicine Research Ethics Committee, Lancaster University (FHM-2022-2182-RECR-2).

Research questions

1. What proportion of patients identified as terminally ill are conveyed to hospital by North West Ambulance Service?
2. What is the association between area deprivation and likelihood of being conveyed to hospital for patients identified as being 'terminally ill' by an ambulance service?

Data

Routine data were extracted from the North West Ambulance Service (NWAS) dataset for all patients for whom the final impression code was 'terminal care' between 01/03/21-28/02/22. The study was restricted to this period because of changes to the NWAS system which meant data prior to March 2021 and after February 2022 was incomparable. The sample size is pragmatic and there was no pre-specified sample size estimation. Data were collected for each patient on demographics (age, gender, ethnicity), geography (Lower Layer Super Output Area (LSOA)), call category (Category 1-5), call outcome (patient seen and conveyed to hospital / seen and treated on scene) and call handler Advanced Medical Priority Dispatch System (AMPDS) codes. AMPDS codes are used by call handlers to initially classify the reason for the call (e.g., 'heart problems'). Place of residence (residential home/family home) was imputed from the incident address by NWAS employees before deleting the address from the dataset. It was not possible to identify multiple calls related to the same individual, meaning that the dataset reflects number of calls made rather than number of individual patients. Area deprivation quintiles were extracted for study LSOA areas from the Index of Multiple Deprivation [11]. For calls made from care homes, the LSOA and corresponding deprivation quintile was selected based on care home location. Call categories 1-5 are UK Government Standards which indicate how urgent the call is, with one being the most urgent and five being the least. The urgency of the category stipulates how quickly the ambulance service should respond to the call.

Data were also collected on the source of the call which enabled identification of whether the call to 999 was made by a healthcare professional (HCP). Calls that could be identified as made by a HCP were excluded because of the different decision-making processes taken by ambulance clinicians for incidents resulting from a healthcare professional call. Data from the areas of Wales included in NWAS' catchment area were excluded because of poor data quality (see Table 1). Full population inclusion and exclusion criteria are provided in Table 1.

Table 1 : Population inclusion/exclusion criteria

	Included	**Excluded**
Origin (professional)	Non-healthcare professional: Emergency Calls, NHS 111 Calls, Police, Fire Service, None recorded	HCP; hospitals, doctor, other ambulance
Category	C1-5	HCP

Age	18+, UNK (unknown)	Under 18
Origin (location)	Home (coded as NA and shared accommodation – needs recoding as Home), Care home (including nursing, residential etc)	Hospital
LSOA	All English LSOAs in dataset	Welsh LSOA: Flintshire (n=1). Only produced NA data. Welsh Index of Multiple Deprivation (IMD) not compatible with IMD

Data analysis

The number and proportion of the study population by age band (18-69, 70-84, 85+), gender (Male, Female), and IMD quintile (20% most deprived areas vs all other areas) were compared to data for the population in the catchment area of NWAS (collected from the Office for National Statistics). IMD was dichotomised to simplify interpretation. This was done after confirming the odds of conveyance were lower in each of the IMD quintiles 2-5 when compared to quintile 1 (most deprived). Distributions were compared for each category (age, gender, deprivation) using Chi-squared tests (statistical significance threshold was $p<0.05$).

Counts and proportions were calculated for categorical variables for all 'terminal care' ambulance calls and by outcome. Rates of calls were calculated per 100K population for local authorities. Univariate associations between patient characteristics and the outcome (conveyance to hospital / treatment at home) were tested using univariate logistic regressions with a p value threshold of <0.05 for statistical significance..

The multivariate analysis was designed to find the simplest model (inclusive of deprivation) that also appropriately represented the inherent structure of the data. Seven models were fitted and compared as follows (also see Supplementary Materials, Table S1): Starting with the simplest configurations, we initially compared models fitted only with fixed effects (deprivation, gender, residential status). We theorised that patient observations were likely to be clustered around geographic location and for that reason included local authority district as a random effect. We also theorised that observations associated with emergency calls would be similar for those categorised the same way by services. Therefore AMPDS codes and call category were also included sequentially as random effects. The large number of group categories for AMPDS would also complicate the analysis of this variable as fixed effects. We believed that residential status could be represented well in either fixed or random effects. We did not specify this beforehand and instead compared model fitting criteria for models that included this variable as either fixed or randoms effects. Deprivation was the main variable of interest and included in every model.

The analysis was stratified by age group to examine the modification effect of age on the model-estimated deprivation coefficient. A stratification approach was used instead of adding an age-deprivation interaction term because age was found to have a statistically significant association with all independent variables in the analysis (Supplementary Table S2). Including an age/deprivation interaction term would only account for an association between these two variables; stratification accounts for the impact of age across all model variables. Stratification enabled us to examine this modification effect but reduced the statistical power of the analysis, as the analysis had to be run separately on the stratified datasets. Therefore, we opted in the final model to include age as a covariate as this would increase the statistical power. Three models were fitted with age and compared: 1) three age groups (18-69, 70-84, 85+) as a fixed effect, 2) three age groups (18-69, 70-84, 85+) as a random effect, and 3) ten year age bands as a random effect (Supplementary Table S3).

Bayesian information criterion (BIC) values were used to initially compare the performance of models, with lower BIC values indicating improved fit based on a balance of higher likelihoods and number of parameters. Likelihood Ratio Tests (LRT) were performed to test whether the observed differences in model fit were statistically significant. Models with a lower BIC value, supported by a statistically significant LRT result, were considered more optimal. Model summaries with test results and sample size are included in supplementary materials. Adjusted odds ratios were generated from coefficients produced by the best fitting model.

Patient and public involvement

Need for research in this area was identified in a previous patient and public involvement (PPI) consultation. A PPI group (n = 20) was consulted at the mid-point and towards the end of the project as PPI funds only became available mid-way through the study. PPI members, drawing on their experiences as carers and relatives, supported the research objective of studying how ambulance clinicians respond to patients with a palliative care need, recognised as a neglected but important area. Preliminary findings were reported to the PPI group, which prompted discussions around the importance of end-of-life-care education for family members and the need for ambulance clinicians to be able to seek advice from an informed contact when a patient does not want to be taken to hospital.

Results

The total number of calls included in the study dataset was 1737. The study population characteristics are described in Table 2. The highest proportion of calls came from people in the 70-84 age band and living in the most deprived quintile. Call handlers used 38 AMPDS codes to categorise initially calls from patients who were ultimately classed under the 'terminal care' impression code by ambulance clinicians who attended the patient. Table 6 reports codes accounting for the highest proportion of overall calls (with at least 5% of calls). Breathing Problems was the AMPDS code accounting for the highest proportion of calls (22%). A full list of all AMPDS codes associated with the study population is provided in Supplementary Materials (Table S4). The study population was significantly older and living in more deprived areas on average than the total population in the NWAS catchment area (Supplementary Materials Table S5). The local authority call rate per 100k pop ranged from 1.04 – 47,7 with a median of 22.9.

Missing data

Roughly one third of patients (34%) were missing ethnicity data (Table 2), which meant ethnicity could not be included in the analysis without high risk of biasing estimates. Seventeen percent of patients in the study population were missing data for gender (Table 2); gender was included in the analysis. No imputation methods were used to replace missing data. A sensitivity analysis was run on the final model removing gender to examine impact on model coefficients and model fit. Excluding gender decreased the size of the coefficient for deprivation (1.43 vs 1.51, Supplementary Table S6) but significantly worsened model fit according to BIC and a Likelihood Ratio Test, resulting in the decision to include gender in the model.

Table 2: Characteristics of patients coded by ambulance clinicians under the 'terminal illness' impression code in the study period

		Study cohort	
Group	*Category*	*number*	*%*
Total Pop	-	1737	-
Age band	0-19	<10	0
	20-29	<10	0
	30-39	18	1
	40-49	36	2
	50-59	124	7
	60-69	272	16
	70-79	430	25
	80-89	524	30
	90-99	305	18
	100-110	20	1
Gender[1]	Female	751	43
	Male	691	40
	Not Available	295	17
Ethnicity	Asian British	33	2

	Black	<10	<1
	Mixed	<10	<1
	Other (not stated)	29	2
	White	1090	63
	Not Available	582	34
IMD quintile	1	683	39
	2	337	19
	3	248	14
	4	276	16
	5	193	11
IMD (20% most deprived areas compared to all other areas)*	1 (most deprived)	683	39
	2-5 (least deprived)	1054	61
Place of residence	Family home	1298	75
	Residential home[2]	439	25
Category of call	Cat 1	770	44
	Cat 2	794	46
	Cat 3+[3]	173	10
AMPDS codes	Breathing Problems	391	23
	Cardiac Arrest [4]	294	17
	COVID	200	12
	Unconsciousness	183	11
	Expected Death	115	7
	Respiratory Arrest	91	5
	Other[5]		

[1] Proportions not including NA: Female 0.52, Male 0.48
[2] Care homes, nursing homes, residential homes, rest homes, sheltered homes
[3] Includes call categories 3,4, and 5.
[4] Cardiac arrest outcomes include both resuscitation attempts and deceased persons
[5] Other includes 29 AMPDS codes that individual represent <5% of the data
*See Table S7 for rates of calls by local authority

Who was conveyed to hospital?

The total number of calls with a terminal care code taken to hospital after calling emergency services was 179, which accounted for 10% of all calls. Univariate analysis suggested that those conveyed to hospital were on average younger, living in a family home, classed as a category 2 call, and from a more deprived area (Table 3). Twelve percent of calls in the most deprived areas were conveyed to hospital compared to 9% in the least deprived areas.

Table 3: Univariate associations between all variables and outcome of call

Group	*Category*	*Conveyed to hospital N (%)*	*Treated on scene N (%)*	*OR (odds of being conveyed over odds of treated on scene) (CI)*	P value
Age band[1]	18-69	66 (14)	392 (86)		
	70-84	75 (11)	628 (89)	0.71 (0.50,1.02)	p=0.06
	85+	38 (7)	543 (93)	0.42 (0.27, 0.63)	p< 0.01
Gender	Female	77 (10)	674 (90)		

	Male	70 (10)	621 (90)	0.99 (0.70, 1.39)	p=0.93
IMD (20% most deprived areas compared to all other areas)*	2-5 (least deprived)	95 (9)	959 (91)		
	1 (most deprived)	84 (12)	599 (88)	1.42 (1.04, 1.93)	p<0.05
Place of residence	Family home	154 (12)	1144 (88)		
	Residential home	25 (6)	414 (94)	0.44 (0.28, 0.68)	p<0.01
Category of call[2]	Cat 1	54 (7)	716 (93)		
	Cat 2	112 (14)	682 (86)	2.18 (1.56, 3.08)	p<0.01
	Cat 3 +	13 (8)	160 (92)	1.08 (0.55, 1.96)	p=0.82
AMPDS codes	Breathing Problems	44 (11)	347 (89)		
	Cardiac Arrest	<10 (<10)	290 (>90)	0.11 (0.03, 0.27)	p<0.01
	COVID	41 (20)	159 (80)	2.03 (1.28, 3.24)	p<0.01
	Unconsciousness	20 (11)	163 (89)	0.97 (0.54, 1.67)	p=0.90
	Expected Death	<10 (<10)	114 (>90)	0.07 (0.00, 0.32)	p<0.01
	Respiratory Arrest	12 (13)	79 (87)	1.20 (0.58, 2.31)	p=0.60
	Other[3]	57 (12)	406 (88)	1.11 (0.73,1.69)	p=0.63
[1] Ten year age bands combined into three age groups due to low cell counts [2] Cat 1 has the highest acuity. [3] Other includes 29 AMPDS codes that individual represent <0.05 of the data					

Characteristics associated with patients living in the most deprived areas

Patients who lived in the most deprived areas were, on average, younger than those in less deprived areas (Supplementary Table S8). However, no association was found, in univariate analyses, between deprivation and category of call or AMPDS code suggesting no difference in urgency assigned between and non-deprived areas...

Multivariate analysis of association between deprivation and hospital conveyance

Unadjusted for age, the best fitting multivariate model included deprivation, place of residence, and gender as fixed effects and AMPDS code group (the initial reason for the call) as a random effect. The local authority district did not improve model fit when included as a random effect. Among the age-adjusted models, including ten-year age bands as a random effect improved the overall fit of the model (Supplementary Table S9). Exponential transformation was applied to the log odds coefficients generated for area deprivation from the age-unadjusted model, for the age-stratified model, and the final model including adjustment for ten year age band as a random effect (Table 4).

In all models, deprivation had a consistent relationship to the odds of being conveyed to hospital. In the final age-adjusted logistic regression mixed model, the odds were 1.51 (95% Cis 1.06 – 2.16) greater among those in the most deprived area than those living in other areas(Table 4). The age-stratified models suggest that deprivation may have a stronger relationship with conveyance to hospital among older patients but the relationship was no longer statistically significant; however, this may be related to the lower statistical power of those models due to the smaller sample sizes.

Table 4: Estimates for deprivation from models where age is a) unadjusted, b) stratified, and c) adjusted by included 10-year age bands as a random effect

Population in model	Age adjustment	Variable[3]	Odds ratio (odds of conveyance from the most deprived areas over odds of conveyance from all other areas)	P value	95% Cis

Full study cohort[1]	Unadjusted for age	Living in the most deprived quintile	1.54	<0.05	1.08 – 2.19
Stratified by age	Age group 18-69 (n=458)		1.42	0.285	0.75 – 2.71
	Age group 70-84 (n=701)[2]		1.32	0.306	0.77 – 2.23
	Age group 85+ (n=578)		1.85	0.106	0.88 – 3.89
Full study cohort[1]	Ten year age bands included as random effect)		1.51	<0.05	1.06 – 2.16

[1] n = 1442 (analysis run on individuals for whom gender was coded)
[2] Fixed effects model used
[3] Odds ratios for all variables included in the model provided in Supplementary Materials (Table S9)

Discussion

The study findings indicate a statistically significant relationship between area deprivation and being taken to hospital for patients coded as 'terminal care' by ambulance clinicians in North West England when adjusted gender, the initial reason for the call coded by the ambulance service, and age (only when grouped in ten year age bands). However, overall, only 10% of patients coded as 'terminal' were conveyed to hospital.

Understanding the relationship between socioeconomic position, palliative care, and use of ambulance services

This study suggests that people in more deprived areas are more likely to be conveyed by emergency services at the end of life than those in less deprived areas [8]. Some evidence suggests that this may be driven by greater health need among those experiencing socioeconomic disadvantage at the end of life [9]. This study did not find evidence that the primary clinical reason for the call, broadly grouped, or the urgency of the ambulance service response, differed by deprivation area. However, given the national clinical guidelines followed by ambulance clinicians, the association between deprivation and transfer to hospital reported in our study may well reflect the more serious nature of the health need among this group. The lower life expectancy and higher prevalence of comorbidities in areas of greater deprivation is a confounding factor that should be taken into consideration in future research on hospital conveyance of this group. Other contributing factors may be hospital being the preferred place of care or perceived as a place of safety [12] or insufficient or poorly supported care at home [13,14].

Patients 'seen and treated' at home by ambulance clinicians

Around 90% of patients whom ambulance clinicians coded as terminal in this dataset were not taken to hospital. This compares to around 40% of patients overall not being taken to hospital by NWAS, according to data published for 2016 [15]. Moreover, the proportion of end-of-life patients taken to hospital by NWAS is much lower than the 70+% reported in an Australian study [16], although this may relate to the narrow coding in our study. Differences between Australian and UK end-of-life transfer rates may also reflect differences in general transfer rates in those countries, estimated as 87.3% and 62% respectively [15,17]. In our study, the COVID-19 pandemic may have impacted decisions to convey patients to hospital. However, a study conducted in a similar time period in London reported much higher hospital conveyance, suggesting that the pandemic impact is insufficient for explaining the low conveyance in North West England[18].

The higher proportion of patients seen and treated on scene can be interpreted positively, arguably reflecting recognition that an emergency hospital admission may not be the most appropriate outcome for this group. However, without an accurate measure of appropriate hospital conveyance, it is difficult to assess this. Furthermore, this raises other questions regarding the time, resource, and skillset required of ambulance clinicians to support a patient, and their family, to receive care appropriate to their needs at home. Doing this

successfully partly depends on having access to palliative care community services, including out of hours care, and collaboration between paramedic and specialist palliative care services [13]. Any improvements in access to, and co-ordination of, quality community end of life care may contribute to lower conveyance rates. As well as system-level and education-based interventions, other studies have shown the need for ambulance clinicians to have access to immediate information and support to help with real time decision-making during an incident [19].

Implications for practice and policy

A large majority of patients in this study, including those from socially deprived areas, were not conveyed to hospital. This warrants further investigation in practice and in research to uncover the possible reasons for this pattern. This research highlights the importance of good end of life care skills among ambulance clinicians. End of life care policies should acknowledge the role of ambulance services in helping to deliver this care and consider ways mitigate any socioeconomic inequities in hospital conveyance. Further research is needed to understand the reasons why patients from socially deprived areas who are terminally ill are more likely to be taken to hospital. Opportunities to use big data held by ambulance services to help explain inequities in management of palliative care patients are underutilised. To advance work in this area, there is a need to find better ways of identifying palliative care populations in ambulance data, beyond relying on codes inputted by ambulance clinicians and likely to identify only those at the very end of life. Initiatives to improve coding of patient characteristics such as gender and ethnicity would enable examination of further inequities, and their intersection with social deprivation, not possible in this study due to poor data quality.

Strengths and limitations

This study benefitted from access to data from the point at which a 999 call was answered to the final impression code entered by a paramedic. This provided an opportunity to look at reasons for ambulance call-outs at the end of life and differences in paramedic decision making association with socioeconomic factors.

The analysis was limited by difficulties identifying a patient population, a problem also reported elsewhere [6], with reliance on a terminal illness code entered by ambulance clinicians. As the use of this code had not been audited or standardised yet by NWAS, this is a limitation to our study. For example, this code would have excluded patients who might have had palliative or end-of-life care needs unrecognised by ambulance clinicians, or not considered as the primary underlying reason for the incident. The decision not to convey may also have contributed to the decision to use the terminal illness code, leading to possible bias in the estimation of conveyance, with greater recognition of terminal illness among those not conveyed than those taken to hospital. It was not possible to clearly identify which of these patients were already dead by the time the ambulance clinicians arrived, which would clearly have implications regarding hospital transfer. It was also not possible to identify if individual patients were making multiple calls; a small number of patients could potentially be making frequent calls. Screening free text data or using data linked to death registrations may be a future solution for identifying a more accurate palliative care population. Qualitative studies exploring how paramedics identify and classify patients as either ‘palliative’ or ‘terminally ill’ would help improve confidence in the use of such codes in routine data analysis.

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Authors’ contributions

MF conducted the analysis and wrote the manuscript. MW extracted the data, cleaned the data, and contributed to the analysis. PD and JS contributed to the analysis. KP, SI, NP supported data collection and interpretation of findings. All authors reviewed and edited the manuscript. No competing interests. MF is the guarantor.

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Competing Interests

Non declared

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