"They shouldn't be coming to the ED, should they?" A qualitative study of why patients with palliative care needs present to the emergency department

Corresponding author:
Dr Emilie Green, Royal Free Hospital, Pond St, NW3 2QG, 020 7794 0500, London, UK, Royal Free London NHS Trust, emilie.green@doctors.org.uk

Co-authors:
Dr Sara E Shaw, University of Oxford, Nuffield Department of Primary Care Health Sciences, New Radcliffe House, Radcliffe Observatory Quarter, Woodstock Road, Oxford, OX2 6GG UK, sara.shaw@phc.ox.ac.uk
Prof Tim Harris, Royal London Hospital, Whitechapel Road, Whitechapel, London, E11BB, UK, Bart's Health Trust, tim.harris@bartshealth.nhs.uk

Word count: 3386

Keywords:
Chronic Conditions, Cancer, Palliative Care, Service Evaluation, Emergency Medicine

Abstract

Introduction: Across the developed world there are concerns about 'inappropriate' use of the emergency department (ED). Patients with palliative care needs frequently attend the ED. Previous studies define the 'reason' for presentation as the 'presenting complaint', which ignores the perspectives of service users. This paper addresses an acknowledged gap in the literature, which fails to examine the decision-making process that brings patients to the ED.

Methods: In-depth narrative interviews were conducted with seven patients (known to a specialist palliative care service and presenting to the ED during a 10-week period) and two informal caregivers. Analysis drew on 'Burden of Treatment Theory' to examine the meaning attributed by participants to their experience of serious acute illness, their capacity for action and the work required to access emergency care.

Results: Five themes were identified about how and why emergency services were accessed: capacity for action, making sense of local services, making decisions to access emergency services, experience of emergency care and coping with change. All narratives captured concerns surrounding the complexity of services. Participants struggled to piece together the jigsaw of services, and were subsequently more likely to attend the ED. Differences between the ways that COPD and cancer patients accessed the ED were prominent.

Conclusion: Further work is needed to understand and respond to decisions leading patients with palliative care needs to the ED, particularly in the context of locally fragmented services, poor signposting and confusion about available healthcare. The perspectives of service users are essential in shaping emergency care.

Introduction

There are concerns across the developed world about increasing and potentially 'inappropriate' use of Emergency Departments (ED). (1-3) Research suggests that overcrowding in EDs can result in poor outcomes and increased mortality. (1-4) There is no consensus on what constitutes an 'inappropriate' ED presentation, and studies attempting to identify the proportion of patients better suited to primary care have quoted figures ranging between 4.8% and 90%. (5-7) The quotation in the paper's title originates from a senior clinician working in the ED of a busy inner city hospital, with concerns about whether and when patients known to palliative care teams should use emergency care.

Many patients are hospitalised in their last year of life, and the majority are assessed and treated in the ED prior to admission. (8) However, there is limited research on ED use among patients with palliative care needs. (9, 10, 11) The existing literature indicates that: cancer patients are reluctant to attend the ED due to the noisy, chaotic environment and heightened anxiety attributed to 'waiting' (8, 12); non-cancer patients may attend the ED because routine care providers are not optimally addressing their symptoms (13-15); services are becoming increasingly fragmented (16) and confusing for patients and staff, potentially leading to more frequent ED presentations (17); better communication across services is needed. (8) To our knowledge, few studies have included patient or carer perspectives. Smith et al. conducted semi-structured interviews with 14 patients and 7 caregivers, but focused on patient perspectives of the ED itself, and did not explore the decision-making process leading to presentation. (8)

Previous studies tend to define the 'reason' for palliative care patients' presentations as their 'presenting complaint' as recorded by ED healthcare professionals. (9-11, 18-23) This approach ignores the social situation, experiences, decisions and emotions of service users, and does not permit a detailed understanding of the reasons that patients with palliative care needs seek emergency care. This paper aims to redress this by examining the decision-making process that brings such patients to the ED. (8, 22)

Methods

This paper reports findings from the qualitative phase of a mixed-methods service evaluation. Quantitative data were initially obtained from the electronic health records of all presentations to the ED made by adult patients known to the specialist palliative care team at an inner city hospital (n=112), referred to from hereon in as 'City Centre Hospital' (Table 1). Data were collected over a 10-week period (08.01.15 to 19.03.15). Findings increased understanding of presenting complaints, but left important questions unanswered about patients' decisions to attend the ED.

Table 1 Overview of 'City Centre Hospital' Trust

- 'City Centre Hospital' is a large inner city NHS hospital, with around 110000 annual Emergency Department attendances. It has an on-site specialist palliative care unit, which provides a range of services in both the hospital and community.
- Referrals to the 11-bedded short-stay inpatient unit for symptom control, respite and/or end of life care are received between 9am and 5pm, Monday to Friday, as doctors are present only within this timeframe.
- Community palliative care services are available to all those registered with a general practitioner in the surrounding borough. Again, clinical nurse specialists (for example oncology, COPD or heart failure nurses) are not accessible during 'out of hours'.
- A consultant telephone advice service is available on a 24-hour basis and can be accessed via the switchboard of each hospital.
- Local services are currently organised such that surrounding specialist hospitals often don't have the capacity to routinely accept patients directly.

Study design and data collection

Due to the lack of standardised criteria, it is notoriously difficult to define and identify patients with palliative care needs. (24) We included only patients known to a specialist palliative care service who had presented to the ED, a sampling approach that was necessary given time and financial constraints. A total of 32 patients from this sample were invited to participate in a one-off interview. Patients were selected purposively to ensure maximum variation in age, gender and primary diagnosis (Table 2).

Table 2 Overview of individual participants (n=7)

Pseudonym	*Age (years)*	*Gender*	*Condition requiring palliative care*
Amira	48	Female	Neuroglioblastoma
Henry	84	Male	Gastric sarcoma
George	68	Male	Chronic Obstructive Pulmonary Disease
Denzel	55	Male	Metastatic disease, unknown primary
Jack	73	Male	Chronic Obstructive Pulmonary Disease
Theresa	69	Female	Chronic Obstructive Pulmonary Disease & Congestive Cardiac Failure
Peggy	70	Female	Chronic Obstructive Pulmonary Disease & Multiple Sclerosis

Of the 32 patients identified, four declined to participate, three had deceased and 18 were uncontactable. This resulted in seven in-depth, face-to-face narrative interviews conducted by EG (female FY2 Doctor). All participants were interviewed in their homes, with two accompanied by their informal carer (both spouses).

A topic guide (Table 3) facilitated interviews, which ranged from 30 to 85 minutes. All interviews were digitally recorded and transcribed, providing a total of 154 pages for analysis.

Table 3 Topic guide
1. Can you start by telling me about how you came to be known to the palliative care team? 2. How are you managing with your illness? 3. Can we talk about your recent visit to the ED? 4. You are under the care of the palliative care team at 'City Centre Hospital'. Are you known to any other healthcare services?

Analysis

We employed a narrative approach to understand the meaning that participants attribute to their experience of serious acute illness and their local ED (25, 26). EG led work searching for themes within and across participant narratives, with SS independently reviewing two transcripts. This process helped us to understand how patients account for their decisions to access the ED. To guide our analysis further we used the 'Burden of Treatment Theory' (27), a structural model of the relationship between sick people, their social networks and healthcare services that recognises that patients must proactively manage their illness and treatment.

The ECAM branch of the Clinical Effectiveness Unit of 'City Centre Hospital' Trust approved this service evaluation.

Findings

We identified five themes about how and why palliative care patients access emergency services: 1; capacity for action, 2; making sense of local services, 3; making decisions to access emergency services, 4; experience of emergency care and 5; coping with change. We describe each of these below, using quotations from interviews to illustrate our findings. Individual and organisational descriptions are necessarily sketchy in order to protect anonymity.

1) Palliative care patients' capacity for action

Patients' functional performance and social skills affect their capacity to mobilise themselves (and their relational network) to access and use healthcare services. (27) Participants talked openly about their illness, it's management, and impact on their everyday lives. Illnesses were discussed in terms of symptoms experienced (e.g. 'pins and needles', 'my head spins', 'my energy levels are still very low', 'pain down his arm, and weakness'), with all seven participants feeling that their symptoms restricted their capacity to participate in activities of daily living including managing their illness and dealing with emergency situations. For example, one female participant with a malignant brain tumour talked of how her illness and treatment (surgery, chemotherapy and radiotherapy) affected her:

> I couldn't climb stairs, I couldn't walk… I've got lots of side effects: the pain in the head, my head spins and my energy levels are still very low, the swelling… the pains… the bladder, it's overactive…I have to keep going to the washroom a lot of times, I can't cope with the foods, I have to eat lots of medication for the vomiting, going to the toilet... That's how it is. And it's very hard for me. *(Amira)*

There was little mention of formal paid carers. All participants were reliant (to varying degrees) on close family relationships (e.g. spouse, son). In three cases this extended to wider family and, in one case, neighbours and friends:

> I rely on my wife, and anyone else that is handy. My wife mainly. We have a car, so I can get around a bit, you know. *(Jack)*

These relationships supported participants with their daily living and helped to maintain a sense of independence and interaction with the social world (e.g. driving to shops). For three of the COPD patients who had sought help from local services for over ten years, this sense of support extended to established relationships with healthcare professionals (particularly COPD and oncology specialist nurses).

2) Making sense of local services

Modern healthcare systems expect patients and members of their social network to identify and understand the diverse activities and tasks that make up 'treatment'. (27) With this in mind, we asked participants to tell us about their experience of emergency services and, specifically, a recent presentation to 'City Centre Hospital' ED. However, participants rarely talked about this instance of care and instead used the opportunity to discuss the network of local NHS services that were – and in some cases were not – available to them. All participants (and accompanying informal carers) found it difficult to decide which services to access in different situations. Participants described needing to invest substantial time and energy to fully understand how local commissioners and providers organise services. For instance, the husband of one COPD patient queried how to access the palliative care team, and their availability:

> I just wondered if… we need to speak to palliative care, which route do we take? Do we ask our GP if she could go in (to the inpatient palliative care unit) for a week or… *(Husband of Peggy)*

All participants described experiences of disjointed care and wanted greater clarity and signposting of services. The lack of continuity of care imposed a heavy burden on patients, who needed to explain, plan and coordinate their care. For example, one female cancer patient talked about the stress of accessing different services:

> I'd appreciate, instead of us having to keep on going to the GP, and trying to explain ourselves again and again, if someone would come with us and express, you know, she's going through this… It just brings a lot of stress, and I think even to a normal person it would, and you just feel that I'm not keeping too well, my energy levels are so low, and what should I do? Stay in bedridden or ask for some support, because I'm not going to get anywhere. *(Amira)*

Participants appeared to misunderstand 'staff roles' within the palliative care system and frequently used the term 'cancer nurse' to refer to their generic nursing care. Many were unsure whether attending nurses specialised in palliative care or oncology, the category of service they were receiving, the institution with which they were affiliated and the accessibility of services. Take the following example from a male COPD patient, who was unsure about his eligibility for palliative care:

> I don't know why I stopped getting palliative care. Someone said to me that palliative care is only for people with cancer *(George)*

Six participants expressed concern that postcode might restrict accessibility and choice of services:

> No the respiratory nurses don't come anymore, because apparently they were from [a different area], in fact they were from the other side of this borderline. *(Theresa)*

None referred to unequal access (e.g. due age or ethnicity).

Ultimately, participants told us that when their symptoms exacerbated, the complexity of services and the work they needed to do to understand how and where to access care made it more likely that they would seek help from the ED.

3) Making decisions to access emergency services

Decisions to seek help from emergency services need to be interpreted against the backdrop of what participants perceived to be a complex network of local services. Both COPD and cancer patients reported being unsure about which service to access when their symptoms appeared to be getting worse. However, accounts of their decisions to seek treatment shifted when they or their carers recognised that there was an 'emergency'. The decision-making process appeared to be different for COPD and cancer patients.

COPD patients and their carers possessed a high level of understanding of their illness. Both parties often recognised that certain symptoms indicated a rapid deterioration of their condition, which quickly led them to access emergency services.

> Oh it's me because I can tell, you know… I can tell by the colour of my, coughing up. *(Jack)*

However, when talking specifically about a recent ED attendance, three of the four COPD patients in our sample described themselves as being too unwell to identify a problem and relying upon a relative to make the decision to attend ED:

> Well, I think, my husband made that decision, or choice, because, I wasn't at all well at the time. I didn't identify it as a problem, until it got beyond a problem! I'm very stubborn. *(Peggy)*

This combination of specific physical symptoms, knowledge about their condition, and support from relatives meant that COPD patients usually went straight to the ED rather than approach alternative services first. Some had previously contacted their GP or the '111' phone line. However, experience told them that this led to hospital admission ("they do her oxygen saturations, blood pressure, and they go, 'you need to go to hospital!'") and so they elected to simplify the process and contact emergency services themselves.

For cancer patients, the route to emergency care was far less clear: more work was required to interpret symptoms, identify a situation as an 'emergency' and access the 'appropriate' services. Like COPD patients, decisions about what to do were often 'collective decisions' (28) involving carers. Unlike COPD patients, cancer patients talked about regularly contacting their GP, specialist oncology team and '111' prior to accessing the ED.

> I phoned the daughter up and told her what had happened... she said 'oh, hold on I'll be round'… so she said 'I better ring up, 111, just to get a bit of advice', so, she phoned them… they said 'well we think he better go to the local hospital', so that's how they got the ambulance. *(Henry)*

> Yes I have got… for the chemotherapy… the emergency number, that's the only number where I can call. And they obviously said go to [the ED]. *(Amira)*

These services were viewed positively by cancer patients, in terms of the advice they received and the relief from responsibility for making the decision to attend ED. However, all participants with cancer indicated that a direct route to oncology or palliative care would be preferable to presenting to the ED, as it would better suit their needs in terms of physical environment and expertise:

> It would be better and advisable to be referred to a hospital where they support cancer patients and they understand cancer patients… 'City Centre Hospital' said that 'we don't

> have any cancer doctors; we don't have any background, what support are we supposed to give you? *(Amira)*

4) Experience of emergency care

Participants with COPD and cancer described different experiences of the ED: the former talked positively about their care and the latter expressed concerns.

COPD patients consistently praised ED staff ('they don't seem to hang about', the nurses, the doctors… they're excellent') and the care they received ('I can't fault it'). They described experiencing significant anxiety during acute exacerbations, predominantly related to breathlessness. This was abated by the ED, which they considered a safe and reassuring environment:

> I think fear plays a huge part, which is why, as soon as you arrive in the ED, you go 'phew, I'm here!' you think, 'someone's going to help me'. It's reassurance. *(Theresa)*

For cancer patients, ED care was not particularly satisfactory. They described long waiting times ('we waited one time for about 12 hours in [the ED]'), an unsupportive environment ('you really don't need that chaos around you when you are already ill'), and concerns over referrals from primary care ('my main concern is the referral…the communication between the GP and the registrar'). Cancer patients and their carers expressed concern that ED staff may be inadequately equipped to address their needs:

> A concern is about the protocol of cancer patients in the ED, especially if they've had chemotherapy. There doesn't seem to be one, at least the nurses don't seem to be really clear about it. *(Wife of Denzel)*

Collecting and handling information

The treatment process often requires patients to manage and communicate information about their condition and care. (27) This was the case for all of our participants, with differences in how COPD and cancer patients handled information.

COPD patients talked with familiarity about emergency services due to frequent admissions throughout a chronic trajectory. Together with their carers, they appeared to predict information needs, seeking to mitigate any issues by preparing answers to questions and taking relevant documentation with them to the ED:

> When she goes in I usually take in the previous discharge summary which covers everything plus her repeat prescription that shows what medication she's on, and we've got a 'not for resuscitation' form as well. *(Husband of Peggy)*

Cancer patients described incomplete or unavailable records ('doctors can't seem to access it', 'They said, "we can't find your file"'), a lack of information sharing ('the system don't seem to coordinate it'), and general dissatisfaction with the informatics system ('that's really quite poor'). This linked with concerns about care within the ED setting and with a desire to receive care elsewhere in emergency situations.

5) Coping with change

Patient experience of illness and treatment is not static. (27) We found that changes in service organisation and provision required participants to frequently renegotiate the care process,

which potentially impacted on their care. For example, one male COPD patient discussed a recent change in the layout of the ED:

> I can't make out this new, the new layout, I just can't… it's like a departure lounge at an airport. *(George)*

Similarly, all participants talked about how changes in their own lives ('you know I was driving up until just before Christmas, but I had to give it up because the medication I'm taking, I get vertigo…') influenced their ability to interact socially and with healthcare services.

Discussion

This study explores how patients with palliative care needs perceive the ED, and examines how the trend towards 'proactive patienthood' requires such patients and their social networks to manage their illness and treatment. (27, 28) Findings show that all participants perceived local services to be complex and inconsistent, and did not fully understand the roles of healthcare professionals or the structure of local service provision. They reported being more likely to attend the ED given the extensive work required to make sense of alternative care options. All participants wanted clearer signposting about services, increased continuity of care and better communication across services; which they felt could help with decisions about when (and when not) to seek emergency care.

COPD patients rarely accessed other services in an emergency situation, electing to go straight to the ED. They adopted a proactive approach, recognised symptoms that indicated a need for emergency treatment and ensured they had relevant information with them. Cancer patients took a more circuitous route to the ED, often contacting other services first. This disparity of service use between malignant and non-malignant disease is a well-recognised phenomenon, (29, 30) and suggests that traditional palliative care models, typically centered on addressing the needs of cancer patients, require adaptation to meet the diverse needs of palliative care patients. (31)

In our study, patients with cancer expressed concerns about the appropriateness of the ED for their situation, specifically that staff would not possess the necessary level of oncology expertise and that they would have to wait for long periods in a noisy, busy environment. Instead, they clearly stated a desire for direct admission to palliative care or oncology units, a preference formerly recognised in the literature. (9, 12) While specialist clinics/inpatient units may be the ideal, numerous challenges hinder direct access, including lack of beds or insufficient staff to admit and manage patients. (31) Further, there is significant geographical variation in service provision, for example with only some facilitating standard interventions such as intravenous infusions. (36)

It is beyond the scope of the article to discuss the appropriateness of each patient's presentation to the ED, however previous research has suggested that frequent emergency presentations may represent a failure of routine palliative care provision. (15, 32, 33) Studies suggest that improved communication between acute, specialist and community services may reduce inappropriate presentations, (9-11) and that adequate advance care planning may reduce unnecessary hospital care by anticipating predictable/potential events. (33) However, outpatient and community settings often don't have the resources to manage acute medical needs, prompting patients to seek assistance from emergency services. (34, 35)

Focusing on patients known to a specialist palliative care team is an accepted research strategy, particularly as previous studies have demonstrated that such patients are often vulnerable to the

same disjointed, non-uniform care as those not receiving specialist input. (37) We accessed a small sample of patients with COPD and cancer, which limits the transferability of findings to all patients with palliative care needs. However, we deliberately collected in-depth patient narratives to ensure a detailed understanding of the reasons behind presentations to the ED, and by using an established theory (27) to guide our analysis, have extended understanding of decision making about ED use among patients with palliative care needs.

Our findings resonate with existing (though currently limited) literature, which indicates that healthcare providers need to look beyond the physical burden of illness and better appreciate how patient response to the demands of illness and treatment affects how they understand and use healthcare services. (27) It is vital that planners and providers take account of (and help to address) patients' reasoning for accessing emergency care. For instance, poor healthcare outcomes and increasing service use are likely when patients are overwhelmed or do not have sufficient resources to cope (27, 38), when urgent outpatient review or direct admission to a specialist inpatient bed is unavailable (11), and when patients experience poor quality routine care. (34, 35) Palliative care is increasingly recognised as an integral component of emergency medicine, and the perspectives of service users are essential in shaping the future of this specialty. (24, 30)

Footnotes

Ethics

The ECAM branch of Bart's Health Trust Clinical Effectiveness Unit approved this service evaluation (registration number 5428).

Acknowledgements

The authors would like to acknowledge Dr Emma Tempest for her input on study design.

Funding

This work was supported by the Isaac Schapera Trust for Medical Research.

References

1. Harris T, McDonald K. Is the case-mix of patients who self-present to ED similar to General Practice and other acute care facilities? EMJ. 2014;31(12):970-4.

2. Richardson D. Increase in patient mortality at 10 days associated with emergency department overcrowding. Med J Aust. 2006;184:213-16.

3. Sprivulis P, Da Silva J, Jacobs I, Frazer A, Jelinek G. The association between hospital overcrowding and mortality among patients admitted via Western Australian emergency departments. Med J Aust. 2006;184;184:208-12.

4. http://www.kingsfund.org.uk/projects/urgent-emergency-care/alternative-guide-urgent-and-emergency-care-system-england

5. Durand A, Gentile S, Devictor B, Palazzolo S, Vignally P, Gerbeaux P, et al. ED patients: How non-urgent are they? Systematic review of emergency medicine literature. Am J Emerg Med 2011;29:333-45.

6. Dale J, Green J, Reid, Gluckman E. Primary care in the accident and emergency department: Prospective identification of patients. BMJ 1995;311:423

7. Foroughi D, Chadwick L. Accident and Emergency abusers. Practitioner 1989;233:657-8.

8. Smith A, Schonberg M, Fisher J et al. Emergency department experiences of acutely symptomatic patients with terminal illness and their family caregivers. J Pain Symptom Manage. 2010;39(6):972-81.

9. Hjermstad, Kolflaath, Løkken et al. Are emergency admissions in palliative cancer care always necessary? Results from a descriptive study. BMJ Open. 2013;3(5):e002515

10. Wallace E, Cooney M, Walsh J et al. Why do palliative care patients present to the emergency department? Avoidable or unavoidable? Am J Hosp Palliat Care. 2013;30(3):253-6.

11. Yates, M. Barrett, A. Oncological Emergency Admissions to the Norfolk and Norwich University Hospital: An Audit of Current Arrangements and Patient Satisfaction. Clinical Oncology. 2009;21(3):226-33.

12. Jelinek G, Marck C, Weiland T, Philip J, Boughey M, Weil J, Lane H. Caught in the middle: Tensions around the emergency department care of people with advanced cancer. Emergency Medicine Australasia. 2013;25:154-60.

13. Ward C. The need for palliative care in the management of heart failure. Heart 2002;87: 294–8

14. Traue D, Ross J. Palliative care in non-malignant diseases. J R Soc Med. 2005 Nov; 98(11): 503–6.

15. Green E, Gardiner C, Gott M et al. Exploring the extent of communication surrounding transitions to palliative care in heart failure: the perspectives of healthcare professionals. J Palliat Care. 2011;27(2):107-16.

16. DOH. Integrated Care: Our Shared Commitment. May 2013. Department of Health, England.

17. Jarrett N, Porter K, Davis C et al. Palliative care patients' perceptions of the work involved in understanding and managing the network of care provision surrounding them. BMJ Support Palliat Care. 2014.

18. Kotajima F, Kobayashi K, Sakaguchi H et al. Lung cancer patients frequently visit the emergency room for cancer-related and unrelated issues. Mol Clin Oncol. 2014

19. Bozdemir, Eray, Eken et al. Demographics, clinical presentations and outcomes of cancer patients admitted to the emergency department. Turk J Med Sci. 2009;39:235-40.

20. Lawson B, Burge F, Mcintyre P et al. Palliative care patients in the emergency department. J Palliat Care. 2008;24(4):247-55.

21. McKenzie H, Hayes L, White K et al. Chemotherapy outpatients' unplanned presentations to hospital: a retrospective study. Supportive Care in Cancer. 2011;19(7):963-9.

22. Barbera L, Taylor C, Dudgeon D. Why do patients with cancer visit the emergency department near the end of life? CMAJ. 2010;182(6):563-8.

23. Mayer D, Travers D, Wyss A et al. Why do patients with cancer visit emergency departments? Results of a 2008 population study in North Carolina. J Clin Oncol. 2011;19:2683–8.

24. Sigurdardottir K, Kaasa S, Rosland J et al. The European Association for Palliative Care basic dataset to describe a palliative care cancer population: Results from an international Delphi process. Palliative Medicine. 2014;28(6):463-73.

25. Muller, J. Narrative approaches to qualitative research in primary care. In: Crabtree and Miller (eds) Doing qualitative research. Thousand Oaks, Ca, Sage.

26. Bauer, M. The Narrative Interview: Comments on a technique of qualitative data collection. 1996. LSE.

27. May C, Eton D, Boehmer K et al. Rethinking the patient: using Burden of Treatment Theory to understand the changing dynamics of illness. BMC Health Services Research. 2014;14:281.

28. May C. Self-management of chronic conditions: re-engingeering patient-hood. Chron Illness 2006;2(1):15-6.

29. National Council for Palliative Care (NCPC) (2014a) National survey of patient activity data for specialist palliative care services, minimum data set for 2012-13 (MDS), http://www.ncpc.org.uk/freedownloads?keys=mds.

30. Dixon J, King D, Matosevic T et al. Equity in the Provision of Palliative Care in the UK: Review of Evidence. April 2015. Personal Social Services Research Unit, London School of Economics and Political Science.

31. A review of Specialist Palliative Care provision and access across London: Mapping the Capital. September 2015. London Cancer Alliance, PallE8, Marie Curie.

32. Earle C, Park E, Lai B et al. Identifying potential indicators of the quality of end-of-life cancer care from administrative data. Journal of Clinical Oncology. 2003;21(6):1133-8.

33. Van den Block, Deschepper, Drieskens. Hospitalisations at the end of life: using a sentinel surveillance network to study hospital use and associated patient, disease and healthcare factors. BMC Health Service Res. 2007;7:69.

34. Grudzen C, Stone S, Morrison R. The palliative care model for emergency department patients with advanced illness. Journal of Palliative Medicine. 2011;14(8):945-50.

35. Field M, Cassel C. Institute of Medicine. Committee on Care at the End of Life: Approaching Death: Improving Care at the End of Life. Washington, D.C.: National Academy Press; 1997.

36. Carlson M, Morrison R, Holford T et al. Hospice care: what services do patients and their families receive? Health Serv Res. 2007;42(4):1672-90.

37. Bakitas M, Doyle Lyons K, Hegel M et al. The Project ENABLE II Randomized Controlled Trial to Improve Palliative Care for Patients with Advanced Cancer. JAMA. 2009;302(7):741-9.

38. May C. The hard work of being ill. Chron Illness 2006;2(3):161-2.