

Transitions to palliative care in acute hospitals in England: qualitative study

Merryn Gott, professor of health sciences,¹ Christine Ingleton, professor of palliative care nursing,² Michael I Bennett, professor of palliative medicine,³ Clare Gardiner, research fellow⁴

¹School of Nursing, Faculty of Medical and Health Sciences, University of Auckland, Grafton, Auckland, New Zealand

²School of Nursing and Midwifery, Northern General Hospital, University of Sheffield, UK

³International Observatory on End of Life Care, School of Health and Medicine, Lancaster University, UK

⁴School of Nursing and Midwifery, St Luke's Hospice, University of Sheffield, UK

Correspondence to: M Gott
m.gott@auckland.ac.nz

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ABSTRACT

Objective To explore how transitions to a palliative care approach are perceived to be managed in acute hospital settings in England.

Design Qualitative study.

Setting Secondary or primary care settings in two contrasting areas of England.

Participants 58 health professionals involved in the provision of palliative care in secondary or primary care.

Results Participants identified that a structured transition to a palliative care approach of the type advocated in UK policy guidance is seldom evident in acute hospital settings. In particular they reported that prognosis is not routinely discussed with inpatients. Achieving consensus among the clinical team about transition to palliative care was seen as fundamental to the transition being effected; however, this was thought to be insufficiently achieved in practice. Secondary care professionals reported that discussions about adopting a palliative care approach to patient management were not often held with patients; primary care professionals confirmed that patients were often discharged from hospital with “false hope” of cure because this information had not been conveyed. Key barriers to ensuring a smooth transition to palliative care included the difficulty of “standing back” in an acute hospital situation, professional hierarchies that limited the ability of junior medical and nursing staff to input into decisions on care, and poor communication.

Conclusion Significant barriers to implementing a policy of structured transitions to palliative care in acute hospitals were identified by health professionals in both primary and secondary care. These need to be addressed if current UK policy on management of palliative care in acute hospitals is to be established.

INTRODUCTION

The UK General Medical Council guidance on end of life care, which came into effect on 1 July 2010,¹ states that doctors must ensure that death becomes “an explicit discussion point when patients are likely to die within 12 months, and that medical paternalism on the subject, however benignly intended, must be replaced by patient choice.”² This advice is in line with policy initiatives that identify a need for health professionals to recognise when patients are likely to

be entering the last year of their life to ensure an appropriately managed transition to a palliative approach to care.³ Within this context a transition is defined as a change of focus in the goals of a patient’s care from “active treatment,” where the focus is on cure or management of a chronic disease, to a “palliative care” approach, where the focus is on maximising quality of life. Most recent models for provision of palliative care advocate a phased transition, with palliative care provided concurrently with active treatment from diagnosis of a life limiting illness.⁴

Researchers in 2006 carried out a systematic review to define an optimum model for transitions to a palliative care approach in cancer.⁵ They identified several steps that healthcare professionals involved in initiating a discussion about transitions with patients should take, although highlight that evidence of practice in this area is sparse. Their recommendations covered a range of topics from preparation for the discussion through to how to conclude discussions appropriately. Although there is increased interest in how transitions to a palliative care approach are, and should be, managed in conditions other than cancer, the evidence here is even more limited, although one study concluded that there is a need for further evaluation of the point for transition to palliative care in heart failure.⁶ A key challenge, particularly in the care of older people, is that the dying phase can often be identified only retrospectively.⁷ Evidence relating to transitions in other clinical contexts is similarly scant. For example, a recent systematic review of transitions to adult services for children and young people with palliative care needs identified that the evidence base here is also poor, with no standardised programmes for transition identified.⁸

Currently, 58% of people in England die in hospital⁹ and this figure is predicted to rise substantially over the next decades.⁹ Repeated hospital admissions for heart failure and chronic obstructive pulmonary disease have been identified as a trigger for transition to a palliative care approach by the Gold Standards Framework prognostic indicators.¹⁰ Although this framework is intended for use in primary care settings, its application within acute hospitals has recently been explored.¹¹ The new *Route to Success in End of Life Care*

guidelines for acute hospitals published by the End of Life Programme advocate “good honest communication,” “advance care planning,” and “access to tailored information” as crucial to optimising the provision of palliative care in this setting.¹² Implicit in these guidelines is a need to initiate a transition to a palliative care approach with patients early in the disease trajectory and to ensure that this information is transmitted to the patient by the clinician who is best placed to have this discussion; it is recognised that in many cases this will be the patient’s general practitioner. Open discussion of prognosis and future care options, holistic assessment, and good communication and coordination of care between different clinicians and settings are considered central to this process.

We explored how transitions to a palliative care approach are currently managed in acute hospitals in England, a currently neglected area of research.¹³ We also considered this in relation to the present policy and evidence based recommendations.

METHODS

Methodological approach

Given the exploratory nature of the inquiry and the limited existing evidence base we adopted a qualitative study design. We used focus groups to capitalise on group interactions and to elicit rich experiential data by exploring participants’ knowledge and experiences.¹⁴ Moreover focus groups are suitable for examining how knowledge and, more importantly, ideas develop and operate within a given cultural context. We held individual interviews with consultants who wanted to participate in the study but were unable to attend a focus group.

Sampling and data collection

Four focus groups (4, 6, 7, and 11 participants) were held at general practices, two focus groups (five participants in each) and four interviews in acute hospitals, and two focus groups (six and nine participants) in hospices. To maximise the sociodemographic diversity of the patient populations we held focus groups and interviews in two English cities: Sheffield and Lancaster. The Royal Lancaster Infirmary serves a predominantly white semi-rural or remote rural population, whereas Sheffield Northern General Hospital services a largely urban, more economically disadvantaged and ethnically diverse area. With the assistance of the researchers, senior medical and nursing staff identified and approached staff at the acute hospitals and hospices. General practices were identified and recruited through local primary care research networks. We used purposive sampling to select a diverse range of health professional involvement and to achieve the maximum possible variation of experience and opinion and reflect the diversity within the population (table). To support the illumination of cultural values informing the work of the team, we held focus groups with members of existing healthcare teams.¹⁵ CG facilitated the focus groups and carried out the interviews. The focus group and interview guide was developed following a review of

the literature and relevant policy and addressed the overall study aim—namely, to explore how transitions to a palliative approach to care are currently managed in acute hospitals in England. The guide covered several key areas: understanding and experience of palliative and end of life care, management and organisation of care, and management of transitions to palliative care (see web extra). The study is the first phase of a project exploring the management of palliative care in acute hospitals in England.

Analysis

With the consent of participants, we tape recorded the focus groups and interviews and transcribed them verbatim. Three researchers read the transcripts individually (MG, CG, and CI), and independently noted down the core themes that emerged. We compared the notes and resolved any discrepancies by consensus. Each researcher took the lead to identify subthemes (MG analysed the themes discussed in this paper). This process was assisted with the use of the data analysis programme NUD*IST, although we considered quotations within the context of the focus group or interview. The coding frame that developed was grounded in the data rather than decided a priori.¹⁶ We identified and discussed divergent cases within each theme. Identified subthemes were then considered in relation to relevant literature. Direct quotations have been selected to illustrate the themes raised by participants and they are indicative both of typical responses and of the diversity of views obtained.

RESULTS

Recognising the point of transition to palliative care

Participants identified that structured transitions to a palliative care approach early in the patient’s disease trajectory advocated in policy are rarely evident in acute hospital settings. Key to changing the focus of care is a discussion of prognosis and all participants

Characteristics of participants in focus group. Values are numbers (percentages) unless stated otherwise

Characteristic	Focus group participants (n=58)
Male	12 (21)
Mean (SD) age (years)	46.3 (9.92)
Age range	28-69
Job title:	
Consultant	4 (7)
Junior doctor	9 (16)
General practitioner	6 (10)
Practice nurse	4 (7)
Clinical nurse specialist	11 (19)
Other nurse	19 (33)
Allied health professional	5 (9)
Place of work:	
Acute hospital	10 (17)
General practice	28 (48)
Hospice	15 (26)
Specialist palliative care unit	5 (9)

reported that such discussions with patients and their families were not routine:

Researcher: And is prognosis routinely discussed with patients in hospitals?

Participant: We never do that . . . I think for a variety of reasons. We don't routinely do that. It's not because we don't want to provide information but quite often breaking bad news to a patient can be pretty difficult . . . and we take a very different approach which may not be right but unless the patient asks their prognosis we don't tell them the prognosis. (Secondary care, location 2, consultant geriatrician)

Timing was identified as a problem, with participants identifying that when a transition to a palliative care approach did occur in hospital, this was typically close to death. A key reason for this was thought to be the hospital's focus on acute medicine:

Sometimes I think that just standing back is difficult to do in acute medicine because you're so taken up with what's in front of you in terms of dealing with investigations and processing people through a conveyor belt really of things that you don't often get the opportunity to stand back and think about it. (Primary care, location 1, general practitioner)

Participants identified that the failure to appropriately time transitions to palliative care could have negative implications for meeting a patient's end of life preferences:

They don't always recognise that yes they are in the last few days of life and that person wants to go home, until the very last minute. Then they ring up . . . like we had one this morning he's coming home tonight, they must have known really from the information that they've given me, that this was going to happen but they leave it until the very last minute. (Primary care, location 2, district nurse)

Participants also reported that, in their experience, a phased transition where active and palliative approaches to care were adopted concurrently was rarely evident in the hospital setting, apart from among patients with cancer receiving palliative chemotherapy. Indeed, an either/or mentality among clinicians about approaches to care was reported:

Some feel that by just doing palliative care we don't need to cure . . . we can just stop everything and just give pain relief and even sometimes they say it's debatable whether to give IV [intravenous] fluids or sub fluids. (Secondary care, location 2, geriatric specialist registrar)

Importance of good communication

Within and between clinical teams and settings

All participants identified the role of good communication in supporting decision making about transition to palliative care as important:

Participant: You have to communicate well to get across that this patient is palliative

Researcher: You mean communication to the patient?

Participant: To the patient, to the family, to colleagues, you've actually got to be able to communicate well. (Primary care, location 1, general practitioner)

A critical first step in this process was seen to be communication within the hospital setting and, in particular, reaching a consensus among all clinicians involved in a patient's care that a palliative approach was now appropriate. The opinion and approach to treatment of the consultant was seen to be pivotal in this respect:

You've got to have some sort of consensus though about how you're going to treat the patient . . . and sometimes I think what happens in a hospital is that the consultant is seen as the be all and end all so their decision is what decides it, whereas actually you need to reach a decree amongst a number of people. (Secondary care, location 1, geriatric specialist registrar)

Problems of power within the professional hierarchy of the hospital were discussed within this context, both between medicine and nursing, and within medicine itself. The need for nursing staff to be provided with opportunities to raise their concerns about the approach being taken to a patient's care was identified:

I think maybe that point when the nurses start triggering and saying "why are we doing this?" it would be nice for them to be able to, I don't know, circumvent or put up a flag so that somebody else gets involved, or some kind of mediator. Because I get a lot of nursing staff telling me "why are we doing this? Why do you keep doing this?" And I say "why didn't you ask yesterday when the consultant was coming round because it would be really nice for you to ask somebody more senior than myself what their intentions are in the situation." But it's well "you're here now, why aren't you doing something?" But actually I am, I'm following the plan that I have available to me and I can question it but I'm still not going to change that unless obviously something significant happens and it's an acute deterioration but I still feel there's a lot of . . . I don't know, stresses in the system. (Secondary care, location 1, geriatric specialist registrar)

The consultant clinicians acknowledged that they found decision making around transition to palliative care challenging:

I think sometimes the transition from an intervention to palliative care sometimes can be pretty daunting for me as a consultant, I don't know what experience you have interviewing others but I certainly find it difficult, and you may have to take a softly softly approach, one step at a time, and then say look the outlook looks grim so we may have to move from there, we need to discuss it with everyone else, with the relatives and everyone

else and see how you can take this forward. I mean it's very difficult. (Secondary care, location 2, consultant geriatrician)

Other participants confirmed that it “took courage” for a clinician to initiate a transition to palliative care:

I think it takes courage to take responsibility for decision making and placing that patient in what might be end of life because they might be receiving palliative care but palliative care itself . . . I guess the decision it has got to be made by someone and I'm not sure that any one person wants to make that decision. (Secondary care, location 2, hospice nurse)

Participants also identified the importance of documenting decisions made to adopt a palliative care approach in the patient's notes. They acknowledged that this rarely happened currently and could represent a barrier to ensuring continuity of care.

Between clinicians and patients and families

Also discussed at length by many participants was the need to improve communication between clinicians and patients about palliative approaches to care:

I think it's the definition of discussion isn't it? It's very different to a consultant than it is to a patient. They go around and say “oh you've got this and this is what's going to happen” and walk off and that's discussed, whereas what the patient wants is to sit down for a good hour or so and ask loads of questions. So although it's appropriate that it's discussed before they come home it's got to be in the right setting. (Primary care, location 2, district nurse)

However, many participants challenged the idea that information on transition to palliative care should routinely be conveyed to patients within hospital settings, advocating instead for the general practitioner to take a lead in these discussions:

Researcher: Do you think that prognosis is routinely discussed with patients in hospitals?

District nurse: No

General practitioner 1: No

General practitioner 2: If it is it's not often

General practitioner 1: My evidence to answer that question is from the patients and I would say no

General practitioner 3: Some patients don't ask and they don't want to know. Because basically you're saying that we aren't on the curative line anymore and I think it takes . . . you don't have the relationship that GPs [general practitioners] have with the patient because you haven't necessarily have known them for a long period of time and you don't know the family whereas often in a community setting you know them and you've known them over a period of time, you've known their relatives, and I think the context is very difficult in hospital, it's much more clinical in the hospital. (Primary care, location 1)

Participants identified particular difficulties in communicating with patients with conditions other than cancer who, it was recognised, were particularly likely to undergo a late transition to a palliative care approach. While they recognised policy guidance on the use of the “surprise question”—“would you be surprised if this patient were to die in the next 12 months?”—they grappled with how to convey this information to patients:

If somebody were to ask you that question—“would you be surprised if they were dead in 12 months?”—well no you wouldn't but you wouldn't be amazed if they were alive either, so you can't communicate that to a patient in a way that's meaningful to them so I think we don't discuss it. (Secondary care, location 1, consultant geriatrician)

That patients typically left hospital with a poor understanding of their diagnosis and prognosis was confirmed by primary care clinicians:

So really it's up to the hospital to make sure that the patients understand their diagnosis, that if they're discharged for palliative care like [patient name] that it's for symptom management and not for a cure because that's what they understand, they believe they're going to be cured. (Primary care, location 1, district nurse)

Primary care clinicians reported that their ability to inform the patient more fully could be compromised by the failure of the hospital to convey treatment information to them in a timely manner:

I think it should be secondary and primary care working together alongside, alongside each other, and the communication is the biggie and unfortunately we still haven't got it right. We're working towards that I know, but I don't think it's still there. (Primary care, location 1, community matron)

Ability to act on expressed preferences about place of death

Finally, participants identified that a further barrier to communicating information on transition to palliative care to patients and their families was the extent to which any preferences for end of life care that were expressed as a result could be acted on:

What I wanted to say is even though we have developments in advanced communications and advanced planning mechanisms that are coming in to help shape some of the decision making, even when you put patients and the families central to that process and they may express themselves that they want to die at home etc, because of a whole host of issues that we've touched on, including resources, that that's just not always possible and a huge percentage of people die in a place that they would chose not to do so. (Secondary care, location 1, hospice nurse)

Indeed, many participants reported that in their experience patients' preferences for place of death, and in particular dying at home, could not always be met for a range of reasons:

People get admitted to hospitals because there's a deterioration in an illness. And there's nowhere particularly for them to go . . . they want to go home but that depends on a lot of communications with the family, the person, the carers, the MDT [multidisciplinary team] to make it possible really and so, with the best will in the world sometimes, people will end up dying in hospital. (Secondary care, location 1, palliative medicine consultant)

DISCUSSION

This qualitative study is timely in shedding light on current practice in transitions to a palliative care approach within acute hospital settings, an issue recently prioritised in UK policy guidance.^{13 12} Central to current recommendations is the need to effect a structured transition involving several steps: recognising when the patient is in the last 12 months of life, understanding the patient has palliative care needs and building consensus within the clinical team as to how these should be addressed, effectively communicating the team consensus to patients and their families, and ensuring patients are offered the opportunities to express preferences for end of life care that are recorded and subsequently acted on. Our data indicate that this approach to transitions to palliative care is far from the reality of practice in acute hospital settings in the United Kingdom.

Main findings and comparisons with other studies

It is unsurprising that participants reported difficulties in recognising that a patient has entered the last 12 months of life, given previous research on clinician barriers to prognostication, particularly in non-cancer conditions,¹⁷⁻²¹ where dying trajectories are typically unpredictable.²² These are difficulties that are not unique to the hospital setting. However, the implications this has for patients' care in acute hospitals have not been previously explored in any detail. Our study found that prognosis does not seem to be routinely discussed with hospital inpatients, representing a key barrier to a structured transition to a palliative care approach being initiated. Moreover, an either/or approach to care was identified, rather than concurrent palliative and curative treatment as recommended in contemporary models of palliative care.⁴

A recent discussion paper has suggested that identification of patients who are in the last days of life may represent a second potential transition point, and that a timely recognition of both the transition to palliative care and the transition to the very end of life are required for optimal care.⁴ These two transition points did seem to be apparent in the data we have presented. Patients with chronic diseases usually present to hospitals with acute deteriorations in their health, and in this

rapidly shifting situation it can be challenging to distinguish correctly between a treatable cause (leading to recovery), a transition to palliative care, or a transition to the last days of life. Furthermore, these two transitions may overlap substantially for some patients. While these situations will occur in primary care, they are probably less common, may occur more slowly, and the patient is likely to be more familiar to the primary healthcare team than to the acute hospital team. These factors might explain the difficulties of hospital teams in recognising a patient's transition point.

The use of the surprise question, as advocated in policy guidance,³ was also acknowledged by participants. However, they reported difficulties in conveying the information on prognosis to patients that was generated by this question. Possible explanations for this include the lack of validation of this screening question at a population level to determine sensitivity or specificity or that participants believed this question was not useful in guiding management at an individual level.

Our study indicates a need for more effective communication within the hospital team to achieve consensus that a patient has palliative care needs and subsequently to use this information to change the care plan. Two key barriers to this being achieved in practice were identified. Firstly, the internal momentum of the hospital directed towards cure was seen to inhibit clinicians from standing back and thinking about the overall goals that should be informing patient care. Secondly, decision making was identified as consultant led, with junior members of the team typically having few opportunities to have input into decisions about transitions to palliative care. Opportunities for nursing staff to feed into such decisions were identified as particularly limited.

Even when consensus on transition to palliative care was achieved within the clinical team, information about such a transition was reported to not be conveyed routinely to patients and their families. That clinicians experience significant difficulties in breaking bad news is well known. Uncertainties about prognosis, unpredictable illness trajectories, and difficulties maintaining hope after such communications have been cited as particular barriers to these discussions across all settings.²³ Our data indicate that training courses in communication skills need to be tailored to the acute hospital setting in recognition of the unique problems identified in this study. Some participants thought that news about transition to palliative care should not be conveyed to patients in an acute hospital setting but rather through discussions initiated by the general practitioner. This is acknowledged in the latest guidance on palliative care management for hospital clinicians; however, the logistic difficulties this poses are not addressed.¹² As primary care professionals involved in our research confirmed, significant barriers to the communication of information from secondary care to primary care settings exist. They identified that the failure of hospital clinicians to inform patients that their condition now required

WHAT IS ALREADY KNOWN ON THIS TOPIC

Policy initiatives have highlighted the need for health professionals to manage the transition from curative care to palliative care appropriately

Empirical evidence relating to this transition is sparse and no studies have addressed this within the acute hospital setting

WHAT THIS STUDY ADDS

Significant barriers to implementing transitions to palliative care within the acute hospital setting exist

Recognition of the transition point to palliative care can be problematic

A lack of effective communication between health professionals and with patients may contribute to difficulties in managing these transitions

palliative care gave patients a false hope of cure. A more realistic recommendation would be that hospital teams provide patients with appropriate information about their condition and its likely progression. Although evidence supports follow-up with the same hospital team after discharge, the involvement of the primary care team at this stage may also be beneficial to ensure that general practitioners follow-up for a discussion about advance care planning.²⁴ Finally, participants identified a concern that initiating conversations with patients about a palliative care approach to treatment could result in patients expressing preferences that cannot always be met. In particular, and in common with previous research,²⁵ participants identified that dying at home is not always achieved, even when information about preferred place of death has been elicited by the clinical team.

Strengths and limitations of the study

To the best of our knowledge, this study is the first to explore how transitions to a palliative care approach are perceived to be managed in acute hospital settings in a developed country. We used purposive sampling to maximise the diversity of participants in this qualitative study; two very different hospital settings were also selected. To maximise the generalisability of our findings to other areas of the United Kingdom we continued data collection until theoretical saturation was reached. However, certain limitations are acknowledged. Participants reported on their practice and that of their colleagues, therefore this was not directly observed. Caution is also required in interpreting and generalising from this data as it is likely that professionals were more likely to participate if they already had an interest in palliative care. Group dynamics within focus groups may have hindered junior staff from sharing their perspectives among senior colleagues. Individual interviews were carried out in cases where participants were unable to attend a focus group, these interviews lack the interaction of a group setting and may not necessarily reflect the views that individuals report among their peers. As all data collection was carried out in England, findings may not be generalisable to other countries.

Conclusions and areas for further research

The findings reported here have significant implications for practice, indicating as they do the level of support that will be needed if current UK policy directives for the management of palliative care are to be implemented within the context of acute hospital settings. Such support needs to encompass not only education and training for generalist palliative care providers, tailored specifically to the unique nature of acute hospital settings, but also a critical consideration of how to deal with the further significant barriers that this study reveals. Indeed, how to ensure structured transitions to palliative care do happen for patients—something which is critical to enabling preferences for end of life care to be elicited and enacted—requires significant further attention by research. In particular, future research could usefully examine interventions that enable all hospital team members to signal a potential transition to palliative care, interventions that encourage communication between hospital teams and primary care teams when patients are admitted to hospital, and patient views about, and experiences of, transitions to a palliative approach to care.

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Data sharing: No additional data available.

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