

The difficulties of discharging hospice patients to care homes at the end of life: A focus group study

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Abstract

Background: Discharge from inpatient palliative care units to long-term care can be challenging. In the United Kingdom, hospice inpatients move to a care home if they no longer require specialist palliative care and cannot be discharged home. There is evidence to suggest that patients and families find the prospect of such a move distressing.

Aim: To investigate the issues that arise when patients are transferred from hospice to care home at the end of life, from the perspective of the hospice multidisciplinary team.

Design: A qualitative study, using thematic analysis to formulate themes from focus group discussions with hospice staff.

Setting/participants: Five focus groups were conducted with staff at five UK hospices. Participants included multidisciplinary team members involved in discharge decisions. All groups had representation from a senior nurse and doctor at the hospice, with group size between three and eight participants. All but one group included physiotherapists, occupational therapists and family support workers.

Results: A major focus of group discussions concerned dilemmas around discharge. These included (1) ethical concerns (dilemmas around the decision, lack of patient autonomy and allocation of resources); (2) communication challenges; and (3) discrepancies between the ideals and realities of hospice palliative care.

Conclusion: Hospice palliative care unit staff find discharging patients to care homes necessary, but often unsatisfactory for themselves and distressing for patients and relatives. Further research is needed to understand patients' experiences concerning moving to care homes for end of life care, in order that interventions can be implemented to mitigate this distress.

Keywords

Nursing homes, hospices, patient discharge, patient transfer, qualitative research

What is already known on the topic?

- In the United Kingdom, there is a cohort of patients who are transferred to care homes for the last few weeks of life;
- Public perception of care homes is poor;
- It is not known how patients experience such transfers, although there is indirect data to suggest that those moving from hospice palliative care units to care home find the prospect distressing.

What this paper adds?

- Hospice palliative care unit multidisciplinary teams recognise the necessity to move patients to care homes for end of life care in order to free up inpatient hospice beds.
- Negotiating such a move with patients and families is challenging, poses ethical dilemmas for staff and can undermine the benefits of safety, security and anxiety reduction achieved during the hospice stay.

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Implications for practice, theory or policy

- Further research is needed to understand patients' and families' experiences of transferring to a care home for end of life care;
- Hospice palliative care units could usefully consider ways to mitigate discharge relocation stress and improve communication between inpatient teams and care home staff.

Introduction

In many countries, specialist inpatient palliative care is provided within short-stay palliative care units (PCUs),^{1,2} and therefore discharge must be considered if patients stabilise. In the United Kingdom and Australia, those who cannot be discharged home are transferred to long-term care settings such as care homes. The limited published literature,³ which largely comprised retrospective audits of patient discharge from UK PCUs, has found such transfers to care homes to be problematic, potentially increasing patient and family distress, while a significant proportion deteriorate before they are ever transferred.⁴⁻⁷

In many Western healthcare systems, transitions between care settings occur with increasing frequency towards the end of life.⁸⁻¹¹ Each transition represents a potential threat to continuity and safety of care.

UK context

A small proportion (5%) of deaths in the UK occur in hospices, while 22.2% of deaths occur in care homes.¹² Hospices have a better public reputation in terms of end of life care: 29% of the public would prefer to die in a hospice, while fewer than 5% would choose a care home.¹³ Public perception of care homes is poor. A public opinion survey undertaken for a recent UK commission on residential care¹⁴ found that only one in four people would consider moving into a care home if they became frailer in old age, while 43% said that they would definitely not move into a care home, which was associated with concerns over abuse, substandard care and institutionalisation. Hospice care is held in high regard by the public, is free of charge and funded by charitable and statutory services; care homes are funded by the individual, unless they have high nursing needs or minimal savings. The small number of hospice beds is reserved for those with specialist needs and are frequently under considerable pressure: triage of referrals is required and discharge if needs can be met elsewhere.

This study aimed to investigate the issues that arise when patients are transferred from hospice to care home at the end of life, from the perspective of the hospice multi-disciplinary team (MDT).

Methods

Question

What are the views and experiences of UK hospice inpatient unit MDTs around discharging patients from hospice to care home for end of life care?

Design

This qualitative focus group study was informed by the researchers' recent systematic literature review³ and clinical knowledge of transitions between settings at the end of life that in turn informed the development of a conceptual framework and semi-structured focus group guide (Appendix 1). Five focus groups were conducted with hospice staff involved in discharge planning at five different hospices (indicated as A to E). Data collection continued until saturation was reached.

Sample

Hospices were purposively sampled to give a range of size and funding structures (see table). All had National Health Service (NHS) contracts to provide care for their local area: two were predominantly NHS funded, two run by local charities and one run by a national charity. Inpatient bed numbers ranged from 10 to 20.

Setting

Focus groups were conducted between May and October 2016. Each hospice team focus group lasted 1 h and took place within the hospice during working hours at a time to suit staff.

Recruitment

Participants were recruited via the lead consultant for each hospice inpatient unit, with a request to include senior decision-making staff and those involved in discharge planning, although any MDT member was welcome. Participating staff were given an information sheet in advance and subsequently gave written informed consent. All the focus groups included at least one senior nurse and one senior doctor, with group sizes ranging from three to six participants (Table 1).

Table 1. Participants in each focus group.

	Number of participants	Designations
Hospice 1	Five	Consultant in palliative medicine, occupational therapist, physiotherapist, staff nurse, discharge facilitator (nurse)
Hospice 2	Six	Consultant 1, consultant 2, occupational therapist 1, occupational therapist 2, inpatient sister, inpatient registered nurse
Hospice 3	Three	Hospice doctor, ward sister, senior sister
Hospice 4	Five	Consultant in palliative medicine, hospice doctor, family support worker, staff nurse, student nurse
Hospice 5	Six	Consultant in palliative medicine, occupational therapist, physiotherapist, family support worker, advance nurse practitioner, staff nurse

Hospice numbers 1 to 5 do not correspond directly with focus groups A to E in the body of the text.

Data collection

Discussions were facilitated by the lead researcher (T.T.) who had conducted a pilot focus group with colleagues and had undertaken training in conducting focus groups for qualitative research.¹⁵ G.C. supported T.T. in running the groups and helped to keep groups to time. Participants were made aware that the lead researcher (T.T.) was a consultant in palliative medicine and that her colleague (G.C.) was a non-clinical social scientist. The discussions were recorded, transcribed verbatim by a confidential transcribing service and anonymised.

Data analysis

A realist, inductive epistemological approach was taken with data analysis, informed by the literature and the lead researcher's (T.T.) experience of working clinically in palliative care. T.T. read and re-read the transcripts to familiarise herself with the data: initial coding was concurrent with data collection, enabling emergent themes to be explored in subsequent focus groups and modification of the coding framework in NVivo software, version 11.1.1 (1551). T.T. made analytic notes and annotated each node. Nodes were rearranged using the data-driven approach of thematic analysis,¹⁶ structuring the data and developing the key themes that were discussed and refined by the research team (T.T., S.B. and G.C.).

Results

The main content of the focus group discussions centred on dilemmas around discharge. This was divided into three themes: (1) ethical dilemmas (divided into three sub-themes), (2) communication challenges and (3) discrepancies between the expectations and realities of hospice palliative care (see Figure 1). There was also some discussion concerning practical issues around discharge that will be presented in a subsequent paper.

Theme 1: ethical dilemmas

Decisions around discharges from hospice PCUs to care homes were fraught with ethical dilemmas. Although not described by staff in such terms, they repeatedly identified scenarios where they felt it was impossible to get it right. Three subthemes were identified: (1) dilemmas around the decision to discharge, (2) lack of patient autonomy and (3) allocation of resources.

Dilemmas around the decision: getting it right for the patient. All participants in all the groups described feeling uncomfortable or guilty about having to present a positive, confident front about care homes, when generally they felt the care would be inferior to the hospice. Some would attempt to give a 'positive spin' by talking about the ability to have more social interaction and not being surrounded by dying patients. However, when patients asked whether the care will be the same as in the hospice, all found it difficult to reassure:

And it's hard isn't it, because you know in reality the answer is that their needs are not going to be met as well anywhere else, and that's really hard isn't it, you're kind of having conversations with patients and families trying to reassure, when you know, generally speaking, actually they're not going to get such a good level of care. (Doctor, A)

Many staff had very negative perceptions of care homes, although those who had first-hand experience tended to be much more positive. It was striking how few hospice inpatient staff had any knowledge of local care homes; negative perceptions were reinforced because they only ever heard about discharges that had gone wrong. Staff discomfort around reassuring patients appeared to be fuelled by misapprehensions and lack of knowledge about the care homes they were discharging to:

There's such bad feeling about nursing homes often because of the media and the stories that it seems quite a negative alternative sometimes I think. (Physio, A)

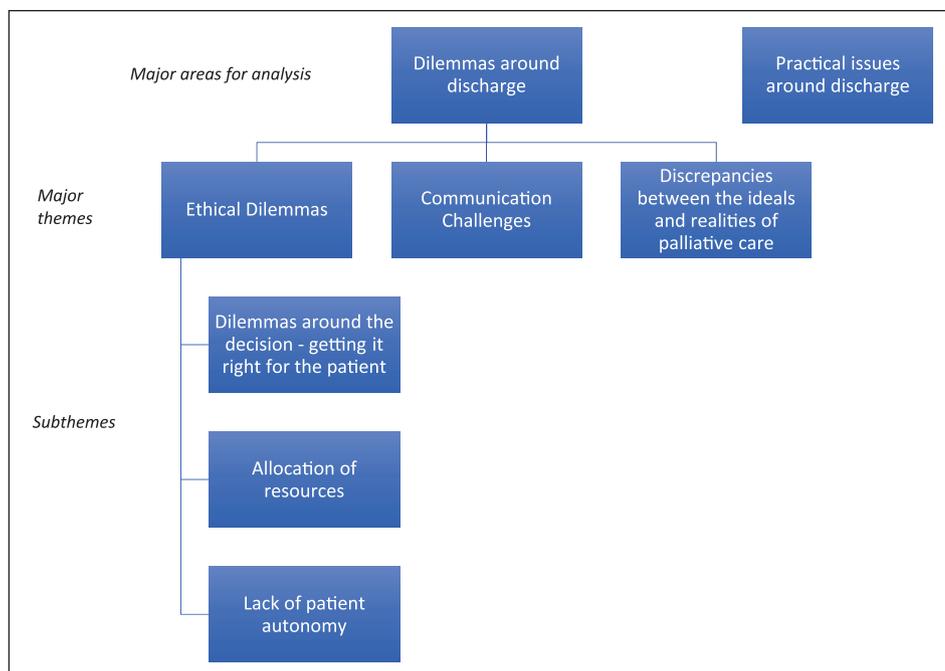


Figure 1. Major themes and subthemes.

A further dilemma was the decision as to whether a patient was stable enough to be discharged. They were often dealing with very frail patients for whom it was very difficult to prognosticate. A significant concern was that the patient would deteriorate rapidly at the new care home and die within a few days: all teams wished to avoid this:

And that's the challenge that we have, yeah, you have to go with your best guess really, accepting that there will be times when you get it wrong. (Doctor, D)

They died two weeks later, but that made me feel bad. I was 'oh God, maybe I shouldn't have'. (Nurse, B)

Allocation of resources: being fair. All teams were conscious of patients with significant needs waiting for hospice admission, and therefore the necessity to discharge those who were stable:

You're conscious of these people that you think, well if we discharge them to a nursing home they might die within the next week or two and ... equally how kind is it on six people on the waiting list in crisis. (OT, A)

Staff had to balance their compassion for patients they had got to know well, with the necessity to take an objective, dispassionate view in order to be fair to patients waiting to come in:

So I think we make the sort of clinical decision regarding homes and then it's often the emotional side is the harder bit. (Physio, C)

Patients and relatives were aware of who was being allowed to stay and who was being discharged. Maintaining consistency with such decisions was challenging, as there could not only be differing approaches within the MDT but also patients could present very differently over the course of 24 h:

Although we don't obviously tell other families what's going on, they talk to each other and then that can cause a lot of issues as well, regarding discharge ... they just don't see it as being fair to them. (Nurse, E)

Lack of patient autonomy. Despite wishing to respect patients' autonomy, it was clear this was often severely restricted. Families had the biggest say over whether a patient could go home, and this, compounded by the lack of availability and funding for home care and the need to discharge from the hospice, meant that the decision to move to a care home was generally imposed on patients, with a restricted choice of care home also. The passive role of patients was a recurrent latent theme, staff describing discussion, conflict and decisions with families far more than with patients. It was not clear whether this reflected patients' ambivalence or that families and carers were more vocal and articulate with staff:

It's not very often phrased as, I moved into a care home, she chose to move into a care home, she wanted to go to a care home, it's always, she was put in a care home ... (Doctor, C)

Theme 2: communication challenges

Participants repeatedly talked of their difficulties over how and when to discuss care home discharge with patients and families. Although all teams aimed to be clear from admission that the hospice was a short-stay unit, often this was either not heard or not appropriate to discuss during a crisis admission:

We have to have a very difficult conversation with the patient and their family saying we know you came here originally for terminal care but we think you've plateaued now. That is not easy for the[patient] because it's, 'okay, how long have I got, does that mean I'm not dying, does that mean I'm dying?' ... which is also difficult for us. (Nurse, B)

A particular issue appeared to be around a subtle distinction between 'dying' and 'actively dying'. Relatives understood their loved ones to be severely ill and yet were being told they were well enough to be discharged:

If it was my mum and someone said 'your mum is dying and is probably going to die in the next month,[but she] is stable', I'd be like 'well for now she is'. (OT, E)

Doctors from all groups described such conversations as extremely challenging: the message was heard by patients as 'you're not dying quickly enough'. Good news that the patient had stabilised became bad news that they would have to move. One patient burst into tears when she was told she was better and could be discharged. For some, greater value appeared to be given to certainty and security over prognosis:

I'm sorry you can't stay here forever, I know you thought that's what you were coming to but you seem to not be dying quickly enough, you know ... people say that to us don't they, 'oh so you're saying that I'm not dying quickly enough' ... I think they're the most difficult conversations we have. (Doctor, C)

Theme 3: discrepancies between the ideals and realities of hospice palliative care

Much of the dissatisfaction with care home discharge appeared to be because staff saw discharge as a betrayal of their high expectations of hospice palliative care. Participants described the benefits of hospice care in terms of security, building relationships, responsiveness and family support. However, discussion of care home discharge removed that security and introduced tension to staff-patient-family relationships, particularly if they felt families were obstructing the discharge process. Staff felt that they were adding to patients' burdens rather than relieving them:

It doesn't sit well with the whole ethos of palliative care does it, where we're in the business of trying to relieve people's suffering and make the last period as good as we can, and we're adding another problem into the mix. (Doctor 1, D)

Staff perceived that patients felt that they were being discarded by the hospice. There was an underlying feeling of guilt that the hospice should look after patients until they died, which in reality was impossible to fulfil, but added to dissatisfaction:

People have set expectations of a hospice don't they, you know, that somehow the hospice will look after you and then once you're engaged with the hospice, the hospice will then become attached to that care. (Family support worker, C)

Many staff were aware that patients felt safe in the hospice and were concerned that patients did not have the energy to build new relationships in a new institution:

They're going to end up in a place where they have got to make new relationships with new staff, at a time in their life when actually they haven't really got the energy to do that ... and probably what's most important to them really is the relationships that they've already got. (Healthcare assistant, C)

Patients had often been asked about their preferred place of care and death, which they had understood to mean they could choose to die in the hospice. Many staff expressed frustration that this expectation added another layer of complexity to discharge discussions:

It also ruins their preferred place of death, if that's the hospice, because we don't routinely admit for [end of life care from a] nursing home unless there's symptom issues. So what we're also saying is 'not only can you not go home, you have to go a nursing home, but we will not be doing our best to try and achieve your preferred place of death'. (Doctor 2, D)

Staff felt that the delays in moving to care homes added further uncertainty for patients in their last few weeks of life, creating a discrepancy between the palliative care premise to help patients 'live well until they die' and the perception that patients were wasting precious time waiting to move:

I find it psychologically for them also very, very difficult, this being in limbo, what's happening you know. (OT, A)

Discussion

Main findings of the study

Discharging patients from hospice PCUs to care homes caused significant dissatisfaction for hospice MDTs

because of ethical dilemmas around the decision to discharge, resource allocation and patient autonomy, the challenge of communicating the reasons for discharge to patients and perceived discrepancies between expectations and realities of hospice care.

Retrospective audits⁴⁻⁷ and interviews with bereaved relatives¹⁷ have highlighted the difficulty of identifying which hospice patients to discharge to care homes. All have shown that a high proportion die before transfer or soon after. One study used multivariate analysis to investigate associations of patient characteristics with survival after discharge from a PCU to a care home. They found that the combination of short length of stay on the PCU, high dependency scores, increasing age and living alone or in a care home prior to admission was associated with reduced survival on discharge.⁴

Prognostication remains a very inexact science:¹⁸ in this study, staff, particularly doctors, acknowledged that there was a high chance they would get it 'wrong'. All teams wished to avoid a patient dying shortly after discharge to care home. Some Australian PCUs have proposed a minimum expected survival of 4 weeks post discharge to care home.⁴

Consistent with public attitudes to care homes, some hospice staff expressed deep unease around the quality of end of life care in care homes and reported similar views from patients and families. Although end of life care in care homes is reported in the literature to require improvement, and many interventions have been developed for this purpose,^{19,20} a recent national survey of bereaved relatives in the United Kingdom found that of those whose loved ones had died in a care home, 82% rated the quality of care in the last 3 months of life as outstanding, excellent or good, and 87% felt that their loved one had died in the right place.²¹ Staff participants in this study who had visited their own relatives in care homes, or been there for professional reasons, could describe homes that were excellent, with devoted and caring staff. It is possible that problematic societal attitudes to care homes create an unnecessary added layer of apprehension for those preparing to transfer to a care home at the end of life.

In this study, as reported in Australia, hospice inpatient teams made decisions around discharge on the basis of patient stability and prognosis. The term 'stability' within palliative care means that the plan of care meets the patient's needs;²² it does not reflect functional status or prognosis. This study highlighted the confusion that arose for patients when told they were stable while simultaneously expecting to prepare for a progressive decline from their terminal illness.

It was notable that staff reported discharging hospice patients to care homes to be more challenging than making difficult decisions or having sensitive conversations about the end of life. Discharge to another institution was perceived to fundamentally reverse many of the benefits of

hospice care and fell below their high standards of good end of life care. Recent health and social care policies have focused on patient choice, control and involvement in decisions,²³ including achieving people's preferred place of death: an impossible request to fulfil for the many people who indicate they would prefer to die in a hospice, and very hard to deny to those already in a hospice and must be discharged to a care home. This study has highlighted how little choice and control patients have over such decisions.

Staff were acutely aware of a perception that patients were being discarded or abandoned by the hospice. The famous quote from Dame Cicely Saunders, the founder of the modern hospice movement, 'you matter because you are you, you matter to the end of your life', creates an expectation that is impossible for hospice teams to fulfil, particularly, in the knowledge that patients were unlikely to be seen by a palliative care nurse on discharge if they did not have specialist needs.²⁴

A recent report on the future of hospice care recommended that hospices should improve their working relationships with care homes 'viewing them as equal partners, providing them with training and education and collaborating with them to enable the delivery of hospice care in the care home setting'.²⁵ Analogies could be drawn between hospice PCUs and hospital intensive care units: both require triage to allocate resources to those with the most complex needs, while discharge must also be carefully managed.²⁶ Initiatives to mitigate such issues have included discharge planning tools, outreach teams, patient and family support, discharge brochures, among others.²⁷

Strengths and limitations of the study

The diversity of seniority and disciplines of focus group participants may have led some to feel inhibited to speak openly in front of their colleagues. This was considered by the study team: the facilitator (T.T.) sought to ensure that all participants were given a voice and offered the opportunity to speak individually afterwards, although none took up this offer. Indeed, the groups' diversity enhanced data collection, with discussions among team members providing valuable insights into team dynamics and decision-making. Although the lead researcher (T.T.) had not worked clinically with any participant, the potential for her role as a consultant in palliative medicine to influence group discussions was acknowledged at the start of each focus group; participants were requested to view her as a researcher rather than a clinician. The potential for the lead researchers' (T.T.) role as consultant in palliative medicine to shape data analysis was mitigated by the involvement of G.C., a non-clinical social scientist, with several unanticipated themes emerging during analysis. While statistical generalisability cannot be argued from this qualitative study, it is striking that the themes were consistent across

all hospice MDTs, despite their differing sizes and locations, supporting the conceptual generalisability of the results.

What this study adds?

To our knowledge, the views of hospice staff on hospice to care home discharge have not been previously reported in the literature. Hospice MDT members clearly find these discharges very challenging. Further research is required to understand patients' and their family members' views and experiences of transfers to care homes at the end of life. It is time for hospices to focus on relocation distress at the end of life, to foster improved relationships between their inpatient staff and local care homes and to focus on better continuity and patient and family support during and after the transfer process, including in bereavement. There is a need for wider recognition that people are frequently admitted to care homes explicitly for end of life care.

Data management and sharing

Anonymised transcripts have been stored electronically and encrypted. Any requests to access the data should be directed to the corresponding author.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethical approval

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