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TITLE: Transferring critically ill patients home to die: developing a clinical guidance document

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CONFLICTS OF INTERESTS

None declared.

KEYWORDS

Critical care, intensive care, end of life care, transfer home to die, dying at home

ABSTRACT

AIMS AND OBJECTIVES

To develop clinical guidance on the practice of transferring patients home to die for doctors and nurses in critical care.

BACKGROUND

With preferred place of care at the time of death a key consideration in end of life care, it is important that transfer home be considered for critically ill patients who want this as part of their end of life care. However there is limited guidance available to inform the transfer of critically ill patient's home to die.

DESIGN

Consensus methodology.

METHODS

At a one day national event stakeholders from cross community and hospital settings engaged in group work where 'virtual clinical teams' mapped out, and agreed on, the processes involved in transferring critically ill patients' home to die. Using two clinical cases and nominal group technique, factors were identified that promoted and inhibited transfer home and areas in need of development. Findings from the day informed development of a clinical guidance document.

RESULTS

85 stakeholders attended the event from across England. The majority of stakeholders strongly agreed that transfer of critically ill patients home to die was a good idea in principle. Stakeholders identified 'access to care in the community' (n=22, 31.4%), and 'unclear responsibility for care of patient' (n=17, 24.3%) as the most important barriers. Consensus was reached on the processes and decision-making required for transfer home and used to inform content of a clinical practice guidance document. This underwent further refinement following review by 14 clinicians. A final document in the form of a flow chart was developed.

CONCLUSIONS

Transferring critically ill patients' home to die is a complex, multifactorial process involving health care agencies across the primary and secondary care interface. The guidance developed from this consensus event will enable staff to actively consider the practice of transferring home to die in appropriate patients.

INTRODUCTION

Delivery of high quality, evidence based end of life care is an international health care priority (World Health Organisation, 2004). However, in many clinical specialities, the evidence base underpinning end of life care continues to develop, and be contested (Department of Health (DH), 2013). As a result many challenges remain as to when, where, and how end of life care can best be delivered (Jin, 2013). Within critical care one area lacking an evidence base is how to honour patient choice and preferred place of care as end of life approaches; especially if the patient's wish is go home to die.

This paper reports on the development of a clinical guidance document concerned with the practice of transferring critically ill patients home at end of life. To inform content of the document a one day national stakeholder event was held. The aim of this event was to gain consensus on best practice in this area and was the final stage of a three phase mixed methods research study. **Phase 1 and 2 of the study are reported elsewhere. (INSERT REFERENCES OF 2 PAPERS PUBLISHED ONCE MANUSCRIPT DECISION MADE)** As the final phase of this study, a stakeholder event was designed to communicate findings of the study to date and undertake an in-depth mapping of the transfer process to inform development of a clinical guidance document. In this paper the stakeholder event is described, the processes used during the event are detailed, and the resulting clinical practice guidance outlined.

BACKGROUND

Despite its traditional technological and curative focus, critical care is increasingly responding to the health policy mandate for high quality end of life. This is evidenced by a growing corpus of work that explores the end of life for critically ill patients, from admission to discharge (Jones 2007; Pattison *et al.*, 2010). A key theme to emerge from this literature is the need to develop robust management plans directed at the decision making and communication processes for patients transitioning from

curative intervention to end of life care (Nelson *et al.*, 2009) and that recognise patient and family choice as central to informing care decisions (Truog *et al.*, 2008).

In health policy, the importance of patient choice in informing decisions about end of life care is evident in such concepts such as preferred place of care (DH, 2005) and advance care planning (DH, 2008). Whilst it is well recognised that, given a choice, most people would prefer to die in their own home (Gomes *et al.*, 2013), less is known about what can happen at the very end of a critically ill patient's life and how patient wishes can inform how and where dying occurs.

There is some published work to inform practice on transferring critically ill patients home at the end of life. This literature reveals strong cultural drivers that influence transfer home with reports focussing on transfer home within the Muslim (Kallel *et al.*, 2006), Maori and Pacific Island (Ryder-Lewis, 2005) and Taiwanese (Huang and Huang 2009) communities. Family involvement in decision making (Tellett *et al.*, 2012) and the need to fully prepare families to understand what will happen post-transfer (Lusardi *et al.*, 2011) are key areas to emerge.

However, reflecting the early adoption of this practice, publications mainly detail single site case reports or case series (Huang and Huang 2009; Clinch and Le 2011; Tellett *et al.*, 2012) and whilst there is some consideration about resources required for transfer, practical guidance for doctors and nurses in critical care is lacking.

AIM OF STAKEHOLDER EVENT

The aim of the stakeholder event was to inform the development of a clinical guidance document for health professionals on transferring critically ill patients' home to die.

METHODS

A national one day stakeholder event was held in the South of England in April 2013. Consensus methodology and nominal group technique informed the processes and activities used during the event. Data gathered from the day informed the content of a clinical guidance document on transferring critically ill patients' home to die. This resultant document was further refined and tested with a group of expert doctors and nurses.

STAKEHOLDER EVENT PARTICIPANTS

Purposeful sampling was used to identify 100 individuals with interest and expertise in transferring patients from critical care home to die. These included stakeholders from **local** primary and secondary care settings; representatives from medical, nursing, allied health (e.g. community pharmacists), commissioners of services, support services (e.g. ambulance staff); representatives of United Kingdom Clinical Networks, professional organisations (e.g. Intensive Care Society) and charities (e.g. Marie Curie Cancer Care), members of the public and **participants involved in the earlier phases of the main study**. Invitations to the event were by email or telephone contact.

Identifying the experience and views of stakeholders on transferring patients home to die

To understand the experience and views of those attending the event on transfer of critically ill patients home to die, stakeholders were asked to respond to four specific questions (Figure 1).

These questions were developed from focus groups that occurred in the early phases of the main study. These focus groups were with doctors and nurses across critical care and community settings, and with service users (INSERT REF). Responses were collected using a 'real time' electronic voting system (Zappers) comprising of small handsets with a USB receiver allowing stakeholders to answer/vote on questions with results immediately graphically displayed using Powerpoint.

INSERT Figure 1: Questions to ascertain to stakeholder views and experiences of transfer home to die

Gaining consensus and identifying priority areas for clinical guidance

Drawing on consensus methodology (Nair *et al.*, 2011), structured group work exercises and nominal group technique were then used to inform development of the clinical guidance document. The group work was led by two experienced facilitators. To map key decision-making processes, stakeholders were asked to consider the question: 'What would need to happen to enable transfer of a critically ill patient home to die?' To facilitate debate about the decision making processes, case vignettes (Figure 2) were used. These were drawn from clinical practice and used with permission of relevant healthcare staff. Vignettes are known to be useful when exploring clinical challenges and complex care issues (Long *et al.*, 2011).

INSERT Figure 2: Vignettes used during stakeholder event

In order to stimulate debate further, stakeholders were pre-organised into nine groups each with a briefed facilitator who was either one of the research team or an experience clinician. Each group was a 'virtual clinical team' with representatives from critical care medicine, critical care nursing, community nursing, palliative care, and a manager or health policy representative. The 'virtual teams' were asked to consider how transfer home could occur and discuss decisions and actions required prior to transfer; during transit; after arrival at home; after patient death. Key discussion points were recorded on flip charts. Groups then fed back on the topic that generated the most debate and the area that needed most development in each case. Nominal group technique (NGT), where organised group discussion identifies and prioritises solutions to a particular challenge (Peña *et al.*, 2012), was then used with the entire stakeholder group to prioritise the areas needing further development in transferring critically ill patients home to die.

Areas of consensus surrounding the processes and decision-making stages of transfer home to die were then collated and organised under the themes of: decisions and actions required prior to transfer, during transit, after arrival at home and after patient death to inform development of a clinical guidance document. Following the meeting a document was drafted and sent to a purposeful sample of doctors and nurses across England with experience of transferring patients home to die and critical care experts for final comment.

For the purposes of reporting on the stakeholder event, descriptive statistics were calculated from data collected through the electronic voting system. Qualitative data were extracted from the flip charts generated by each group, collated and content organised under the themed stages of the transfer process.

RESULTS

The stakeholder event was attended by 85 people (excluding research team members). Participants were predominantly clinicians (doctors and nurses) from a range of secondary care trusts (n= 57) across England and from primary care trusts or palliative care teams (n=18) predominantly located within the south of England. The remaining participants were allied health professionals (n=4) that included ambulance staff, and policy stakeholders and service users (n=6).

The experience and views of stakeholders on transferring patients home to die

All stakeholders were asked to respond to questions to identify their experience of, and views on transferring critically ill patients home to die. Of the 71 stakeholders who responded to the questions, 18.3% (n=13) indicated they had experience of transferring a patient home to die from critical care. Almost half of responding stakeholders (49.3%, n=35) had not transferred a patient

home but had been involved in discussions about possible transfer. A further 32.4% (n=23) did not have any experience in this area.

When asked about their views on transfer home, most stakeholders (n=36, 52.2%) strongly agreed that it was a good idea in principle and most (n=49, 69.0%) strongly disagreed that it was a waste of health care resources. Regarding significant barriers to transfer home, 'access to care in the community' (n=22, 31.4%), 'unclear responsibility for care of patient' (n=17, 24.3%) and 'unrealistic expectations of relatives about death at home' (n=8, 11.4%) received the most responses.

Gaining consensus and identifying priority areas for clinical guidance

As described earlier, nine 'virtual clinical teams' considered case vignettes to answer the question: 'What would need to happen to enable transfer of a critically ill patient home to die?' Organised around the four key stages of transfer, discussions with patient/family and other hospital and community based teams emerged as important areas (Table 1).

INSERT Table 1: Examples of data from stakeholder event in response to the question 'What would need to happen to enable transfer of a critically ill patient home to die?'

Issues that generated the most discussion during the vignette group work focussed on: the importance of planning prior to discharge and the challenge of making assessments of capacity in critically ill patients. Areas identified as needing the most development included the need for: a single person/point of contact to lead on transfer arrangements; increased understanding of the available community care and care packages at home; further information about commissioning and funding for this initiative; and improved guidelines on the practicalities of handover and withdrawal of treatments (e.g. in the unit or at home). Using nominal group technique, stakeholders ranked

these to identify the areas needing priority development to inform practice. Increased understanding about community support services (30.3%) was identified as the number one priority.

After the stakeholder event, a clinical guidance document was developed informed by the group work. The document was drafted in two formats; a linear flowchart and a 'funnelled' decision-making tree and structured around 5 key phases: assessing potential for transfer home; preparing for transfer; during transfer; on arrival home, and after death. These two formats were sent to 14 doctors and nurses across England with experience of transferring patients home to die and critical care experts. **These were all participants involved in the earlier phases of the main study.** In follow-up telephone interviews this group recommended use of the flow chart version, and made suggestions regarding its potential use e.g. as a tool to be used with families and patients to explain the decisions-making processes and risks involved. The clinical guidance document can be accessed via [web address removed for peer review].

DISCUSSION

The aim of the stakeholder event was to bring health professionals together to reach consensus on the process of transferring critically ill patients' home to die in order to inform development of a clinical guidance. Stakeholder events are well recognised as an effective methodology to achieve consensus (Keown *et al.*, 2008) where participants have opportunity to discuss, prioritise and consolidate areas of agreement (Ager *et al.*, 2007). As such, this stakeholder event provided the research team with a high level of practical detail about the process of transferring patients home to die.

A key area raised in the stakeholder event was the importance of patient and family choice in decision making. Resonating with the literature, there was a strong emphasis in the stakeholder discussions on the patient's capacity to undertake decision making (Lusardi *et al.*, 2011) and on the

clear need for family engagement at all stages of the process (Tellett *et al.*, 2012). Interestingly, whilst communication with the family after the transfer has been identified by some as a crucial element of transferring home to die (Lusardi *et al.*, 2011), this was less well explored by stakeholders. Similarly the importance of culture, often reported in the literature as a strong influencer on decisions to transfer home at end of life (Ryder-Lewis, 2005, Kallel *et al.*, 2006, Huang and Huang 2009) was not profiled in the group work *per se*.

A further key area of discussion during the stakeholder event was the suitability of patients for transfer. In particular discussion and feedback on the clinical vignettes used during the stakeholder event, drew attention to the important distinctions between intubated and non-intubated patients and of conscious and unconscious patients. As others have noted Kompanje (2009), this raised questions about patient, family and staff motivations for transfers of critically ill patients home to die.

Knowledge about community services and how doctors and nurse in critical care could access these was also a key issue for stakeholders. This is not surprising given that knowledge about discharge processes to the community is known to be problematic for hospital-based nurses (Nosbusch *et al.*, 2010). Similarly, whilst intra-hospital and inter-hospital transfer processes are generally well established for critically ill patients (Fanara *et al.*, 2010), co-ordination and integration of care for critically ill patients across the secondary-primary interface has received little, if any, attention.

Findings from the stakeholder event demonstrate that transfer to community services is perceived to be a complex, time dependent process. However, understanding the challenges this patient-centred initiative might present enables novel solutions to be developed e.g. critical care nurses undertaking verification of death (Battle *et al.*, 2014). It may be that with greater understanding of community-

based systems and the existence of clinical guidance may enable effective and efficient transfer by staff who do not routinely engage in this practice.

CONCLUSIONS

There are key issues for clinicians to address when making decisions about transferring critically ill patients home to die. These include making assessments about a patient's clinical suitability, addressing the logistics of transfer arrangements to the community, managing unrealistic expectations of families of patients' dying at home, and preparing families for what will most likely ensue.

In order for transfers home to be a feasible option, critical care staff need to understand the nature of hospital and community-based services and have the means to mobilise these, often within an extremely short time frame. This clinical guidance document may provide a platform from which individual units can review and plan a local response to transferring critically ill patients' home to die, thereby prompting the development of effective links and working relationships with rapid discharge and palliative care teams. Whilst further work is required to test the usefulness and implementation of the clinical guidance document, it is hoped that knowledge of this resource to support decision making may raise awareness of the practice of transferring critically ill patients home to die, thereby enabling some patients to have greater choice in their preferred place of care at end of life.

WHAT IS KNOWN ABOUT THIS TOPIC

- Case studies are available that identify transfer of patients home to die is occurring in critical care settings.

- Little is written or available to inform doctors and nurses about the practicalities on how this can be achieved in practice.

WHAT THIS PAPER ADDS

- Consensus methodology can be used with stakeholders to inform development of practice guidance documents.
- Expanded clinical networks that cross primary-secondary care boundaries are needed when planning complex discharge outside of a normal critical care transfer pathway.
- Doctors and nurses from critical care across England have informed the development of a clinical guidance document for transferring the critically ill patient home to die.

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