

An investigation about transferring patients in critical care home to die: experiences, attitudes, population characteristics and practice.

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Background

Providing patients at the end of life with choice regarding where they die has become an important goal of health services as research reports that the majority of people, when asked, express a preference to die at home. Currently, however, most people die in hospital.

A proportion of hospital deaths occur in critical care areas where transferring a patient home to die, whilst a potential option, is rarely undertaken. Low transfer rates are likely to be influenced by the severity of the patient's condition and associated treatment and care which limits the time available to consider and organise transfer. In countries other than the UK transfer home to die is reported in small numbers and linked to cultural norms and expectations related to what end of life care should entail, who should be involved and where death should happen. Relatively little is known about what is needed to facilitate this practice. Furthermore, what the current level of provision in the UK is, and whether this option is one that health care professionals are able and willing to facilitate, is also unclear.

Aims

The study aimed to scope the experience, attitudes, and views of critical care health care professionals regarding the feasibility of transferring critical care patients home to die. The objectives for the study were to:

1. Investigate current experience of, practices related to, and views towards transferring critical care patients home to die
2. Identify factors that enable or challenge service providers to transfer patients in this care setting home to die
3. Scope the size and characteristics of the potential 'transferring patients home to die' critical care population
4. Explore factors that might influence the feasibility of transferring critical care patients' home to die, including resources and infrastructure required
5. Make recommendations on models of care/service specifications in this area.

Methods

The study was carried out in three phases.

Phase I included a review of the literature with findings subsequently being used to explore this topic in six focus groups carried out with: i) health care professionals from critical care, ii) health care professionals from community services, and iii) members of a patient and public forum. Focus groups aimed to gain information about experiences of, and views and attitudes toward, transferring patients home to die from critical care settings.

After completion of the focus groups a web-based survey was developed and an invitation to participate was sent to lead consultants and nurses (756 individuals) working in 409 critical and high care units across the UK. The aim of the survey was to: establish the current level of transfer activity in UK, identify how many critical care staff had direct experience of organising a transfer home from their unit, and what attitudes, views and concerns are related to providing this service. A further aim was to establish what level/type of care/treatment would facilitate or obstruct potential transfer home to die in this population. Participants were asked to rate their top five facilitators and barriers to transfer from a list of 11 options.

Following on from the survey, individual telephone interviews were carried out with 21 doctors and nurses who had been actively involved in transfer/s, or had been involved in discussions about the possibility of transferring a patient home to die. These interviews aimed to identify the practical issues that needed to be considered when providing this type of service, and the factors that they indicated as facilitating or obstructing a transfer.

Phase II involved an audit of medical records of 7,844 patients who were inpatients in 7 critical and high care units at two hospitals in the South of England over a one year period. The audit aimed to identify: the number of patients who died on the units, and of these, how many patients (if certain criteria applied) could potentially have been offered the option of being transferred home to die.

Phase III convened a national Stakeholder Event of 85 representatives from professional organisations, critical and community care health care

professionals, patients and relatives. Vignettes were used to stimulate discussion as a further aim of the Stakeholder Event was to identify models of care, potential elements of a service specification and clinical guidance to inform practice in this area. In addition, a nominal group technique aimed to identify and prioritise barriers most likely to influence transferring patients from critical care home to die, as well as prioritise areas within the process that required further development.

Results

Phase 1 Literature Review

The literature review found there are few published studies that report the transfer of patients home to die from critical care units, and those that are available have small sample sizes or articulate case studies that illustrate the influence of cultural factors on the decision making process and service provision. The current literature lacks detail of the procedure involved in transfer, and critique or evaluation of the process.

Phase 1 Focus Groups

Whilst focus group participants held positive views about transfer home to die from critical care, this was an uncommon event and was perceived to be a complex process. Due to the majority of focus group participants having little or no experience of transfer home to die the key issues raised by clinical participants included: the problems associated with identifying suitable patients, lack of knowledge of how to coordinate transfer arrangements to the community, managing unrealistic expectations of families related to how death at home might proceed, and an urgent need for guidance to inform service development. Key drivers associated with implementing transfer included: patient and/or family request, support for the idea from family members (when patient has initiated the request), and access to care in the community.

Phase 1 Web-based Survey

Of the 756 critical care staff invited to participate in the survey 191 (25.3%) participated, with 180 (23.8%) respondents providing sufficient data for analysis. Of these 180, 71 (39.4%) were consultants and 97 (59.9%) were

nurses. A minority of respondents 65 (36.1%) had been actively involved in transferring patients home to die and only 28 (15.5%) had had been involved in discussions about this possibility.

The survey indicated that respondents were supportive of the idea of transfer home to die and that in terms of patient characteristics patient stability was a key factor in decision making.

The top three ranked barriers to transfer were: i) lack of access to care in the community, ii) patients' relatives unlikely to be able to cope with transfer and death at home and iii) lack of guidelines on transfer home to die.

Phase 1 Follow-on Interviews

Those participants who had experience of transfer were positive about the feasibility of offering this service and saw it as an important part of end of life care in appropriate circumstances. Findings indicated that the request for transfer home usually came from family members and patients. Interview participants indicated access to care in the community and relatives' ability to cope with care at home were key factors during decision making. Participants indicated the need for a named clinician to lead in liaising with individuals across clinical, organisational and geographical boundaries if transfer was to be successful. Participants also stressed the speed at which services and equipment could be identified, accessed, orchestrated and implemented was a crucial factor in facilitating transfer home to die.

Participants who had carried out transfer reported effective links and working relationships with rapid discharge and/or specialist palliative care teams expedited transfer home as these teams were able to identify and deal with the relevant legal, health and safety and ethical issues arising from a decision to transfer a patient home to die. Aftercare was also identified as important from the interview findings.

Phase II Audit

Of the 7844 patients' notes audited: 422 (5.4%) patients had died. Patients were identified as unlikely to be suitable for transfer if certain pre-determined

criteria were identified in their notes and these included: cardiac arrest or sudden death (n = 62 patients, 14.7%); instability as judged against agreed audit criteria (n = 225 patients, 53.3%), and 35 (8.3%) due to other factors (coroner's cases, complex family dynamics, and high level of nursing care needs). Therefore a total of 322 (76.3%) patients were unlikely to be considered for a possible transfer, leaving 100 (23.7%) patients who, judged against the audit criteria, could have been transferred home to die as they were clinically stable and did not present with specific physiological or care factors. None of the 100 patients identified as potentially suitable through this process were transferred.

Phase III Stakeholder Event

When healthcare professionals were asked to prioritise what they saw as the top three barriers to transfer the barriers were similar to those identified during earlier phases of the study and included: access to care in the community; responsibility for care of patient, and expectations of relatives about death at home. In addition, participants were asked to identify the area that needed the most development to enable the practice to be more fully developed. The following three areas were prioritised: 1) increased awareness of community support services (30%), 2) refine transfer process (15%) and 3) look at new activities/pathways (14%).

The event was a success from the researchers' point of view and served to generate a level of detail about the transfer process that combined with findings from each phase, informed development of clinical guidance.

Phase III Guidance

Findings from the study were used to generate clinical guidance that relates to considerations for the transfer process. Two different formats were developed and presented to experienced clinicians (n=14) for initial testing. The guidance was generally well received by clinicians but clinicians differed in their views on how it might be used. Some suggested a version of guidance for use in discussions with patients and relatives, others as a potential educational tool (developing awareness for this practice on the unit and the processes necessary to underpin the practice). Clinicians saw the benefit of

having clear guidance to aid the organisation of transfer home to die. A final version was developed incorporating suggestions provided by the experienced clinicians.

Conclusions

To our knowledge this is the first study internationally to conduct an in-depth examination of the concept of transferring patients from critical care home to die, and whilst there have been initiatives to improve end of life care in the critical care environment these have not extended to consideration of preferred place of death.

The study has scoped the size and characteristics of the critical care population with potential to transfer home to die and found that very few patients are offered or request this option. Findings clearly indicate the positive view of health care professionals toward the possibility of transferring patients home to die with physiological stability of the patient, as well as psychological, social, spiritual and contextual factors playing an equal role in the decision making process.

The logistics of transfer to community services is uniformly perceived to be a complex, highly time dependent, process which currently lacks evidence based guidance to enable and direct practice in this area. A lack of guidance and the availability of tools to facilitate the transfer process may be contributing to critical care teams not routinely considering the option of transfer home to die.

Recommendations for practice

Findings from the study have generated clinical guidance that relates to considerations for the transfer process. In order to further develop practice in this area we recommend:

- Staff in critical care environments actively consider the practice of transferring patients home to die

- Clinical teams in secondary and primary care use the guidance as a point of reference to develop local policy and procedures to underpin the process
- Critical care units establish which local (both secondary and primary care) resources might be mobilised in the event of a transfer being considered and engage with stakeholders in discussions and clinical policy development. These should address cases where death will be very rapid once the person reaches home but also where a longer dying trajectory is anticipated (or occurs unexpectedly)
- A community of practice be established whereby the experiences and solutions to effecting rapid and effective transfer can be shared between units with the aim of developing practice in this area

Recommendations for further research

The efficacy and usability of the guidance generated in this study needs to be tested in an implementation study carried out in conjunction with critical care units and their linked community care providers.

In addition, work is needed to better understand the experiences and practices of community-based staff in relation to caring for patients who have been transferred home to die from critical care.

Equally, it is essential to understand what happens once transfer has taken place and how events are managed in the home before and after death. This should include examining the process and outcome from the perspective of family members of which little is known.

Finally, implementing any change in healthcare practice is fraught with challenge as barriers to implementation can arise at multiple levels of care delivery: the patient and family level, provider team level, organisational level or policy level. Studies to develop and evaluate tools to help healthcare teams, patients and their families consider how suitable the option of arranging for a person to die home might be in a particular case are necessary.