Doctors and nurses views and experience of transferring patients from critical care home to die: a qualitative exploratory study.

Dr Maureen Coombs
Professor in Clinical Nursing (Critical Care)
Graduate School of Nursing, Midwifery and Health
Victoria University of Wellington
Wellington, New Zealand
(Formerly of Faculty of Health Sciences, University of Southampton)

Dr Tracy Long-Sutehall
Faculty of Health Sciences
University of Southampton, Southampton, UK

Dr Anne-Sophie Darlington
Faculty of Health Sciences
University of Southampton, Southampton, UK

Professor Alison Richardson
Faculty of Health Sciences
University of Southampton, Southampton, UK

Abstract

Background: Dying patients would prefer to die at home and therefore a goal of end of life care is to offer choice regarding where patients die. However, whether it is feasible to offer this option to patients within critical care units and whether teams are willing to consider this option has gained limited exploration internationally.

Aim: To examine current experiences of, practices in, and views toward transferring patients home to die in critical care settings.

Design: Exploratory two stage qualitative study

Setting/Participants: Six focus groups were held with doctors and nurses from four intensive care units across two large hospital sites in England, General Practitioners and community nurses from one community service in the south of England and members of a Patient and Public Forum. A further 15 nurses and 6 consultants from critical care units across the UK participated in follow-on telephone interviews.

Findings: The practice of transferring critically ill patients home to die in the UK is a rare event despite the positive view of health care professionals. Challenges to service provision include: patient care needs, uncertain time to death and the view that transfer to community services is a complex, highly time dependent undertaking.
Conclusion: There are evidenced individual/policy drivers promoting high quality care for all adults approaching the end of life encompassing preferred place of death. Whilst there is evidence of this choice being honoured and delivered for some of the critical care population, it remains debatable whether this will become conventional practice in end of life in this setting.

What is already known about this topic?
- Empirical work on transferring critical care patients home to die is currently limited to case reports or small scale single site studies
- Little is known about the views and experiences of critical care teams regarding the feasibility of transferring a critical care patient home to die

What this paper adds:
- Doctors and nurses in critical care are generally positive about transferring critical care patients home to die
- The decision to transfer critical care patients home at end of life is complex requiring consideration of the patient's dying trajectory, family preparedness and knowledge of available community care services.

Implications for practice and future research:
- Transferring patients home to die is feasible and staff in critical care environments should consider this option as part of end of life care for some patients.
- Evidence generated from this study provides a point of reference to inform the development of local policy and procedures to underpin the practice of clinical teams in secondary and primary care.
- Further research is needed to 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, along with examination of process and outcome from the perspective of family members, of which little is currently known.

Keywords: Critical Care, Doctors and Nurses, End of Life Care, Transfer home

Introduction

Providing patients with choice about where they die has become an important goal of health services [1, 2] as, despite reported preference for a home death [3], the majority of people in the UK die in hospital. Furthermore, the literature suggests that in Intensive Care Units (ICU) and High Dependency Units (collectively referred to here as critical care units (CCU),   transferring a critically ill patient home to die is rarely undertaken.

The literature exploring the prevalence and practice of transferring patients home to die in the UK is very limited [4, 5, 6, 7]. International evidence about this practice is small-scale, reporting on the experiences of critical care units from Netherlands, Tunisia, New Zealand, Taiwan, where this option is offered [to varying degrees] and is generally seen as a positive initiative. The literature indicates that the prevalence of transferring patient's home to die is low and that strong cultural drivers influence the decision to transfer home. This initiative is reported as especially important in the Muslim [8,9], Maori and Pacific Island [10], and Chinese[11] communities Whilst patient preference and family choice [12, 4, 13, 14] are also reported as drivers, the literature highlights that this initiative is limited by specific patient characteristics such as whether the patient is ventilated, haemodynamically stable (15, 16).

In view of the limited evidence base (both in quantity and quality) available to guide clinical practice in this area, a three phased mixed methods study with positivist (quantitative) and interpretivist (qualitative) data collection and analysis arms was designed with the aims of: i) scoping the size and characteristics of the potential transfer home to die population in UK critical care units , ii) Investigating current practices related to transferring critical care patients home to die, iii) Identifying factors that enable or challenge service providers to transfer patients in this care setting home to die, and iv) exploring the experiences, attitudes, and views of critical care doctors and nurses regarding the feasibility of transferring critical care patients home to die (17).

This paper reports findings from the qualitative arm of the study where the objectives were to:

- Examine current experiences of, practices in, and views towards transferring patients in critically care areas home to die
- Identify factors that enable or challenge the ability of service providers to transfer patients in this setting home to die.

Design

The qualitative exploratory arm of the study consisted of two stages. Focus groups (Stage 1) were undertaken to gain a broad representation of views toward, and experience of, transferring patients home to die from critical care environments. Telephone interviews (Stage2) were carried out to gain a detailed description of the transfer process, for example: what was done, why it was done and what halted transfers. Findings from Stage One informed the development of questions that guided data collection in Stage Two. Qualitative content analysis (18) was the analytic technique of choice for both stages of analysis. Ethical approval to carry out the study was gained via IRAS (REC reference 11/SC/0031) and R&D approval secured via site specific procedures.

Methods

Data collection - Focus groups

Recruitment – Doctors and nurses from four critical care units across two large hospital sites in England were invited to take part in focus groups. General Practitioners (GPs) and community nurses attached to a community service in the south of England were

recruited to a further focus group. Members of a Patient and Public Forum (PPF) were also approached to take part in a dedicated service user focus group (Table 1).

Participants - 49 participants took part in six focus groups: i) General CCU [n=7]; ii) Cardiac CCU [n=10]; iii) Neurological CCU [n=11]; iv) Oncology CCU [n=8]; v) GPs and community nurses (n=6); vi) members of the PPF (n=7).

Procedure - Focus groups were organised to coincide with staff meetings or PPF meetings over a three month period in 2011. Written consent was gained prior to commencement of the focus groups. The researcher (ASD) facilitated all focus groups with an observer role taken by members of the research team (MC, TLS). A vignette was used to stimulate discussions in focus groups with critical care or community HCPs only. A semi-structured focus group guide was used with all groups (Table 1).

Table 1 Focus group participants, vignette and question schedule.

Focus group	Discipline	Participants	
1	General ITU	Nurse = 5 Consultant = 2	**Vignette** A 65 year old man is critically ill and is not responding to treatment. Treatment withdrawal is discussed with the family and they would like him to die at home.
2	Cardiac ITU	Nurse = 6 Consultant = 4	
3	Neurological ITU	Nurse = 9 Consultant = 2	**Questions** What are your views about transferring critically ill patients home to die?
4	Oncology	Nurse = 6 Consultant = 2	Do you think it is important/feasible to transfer critically ill patients home to die? When would you transfer a critically ill patient home to die? When would you NOT transfer a critically ill patient home to die?
5	General Practice	Nurse = 1 GP = 5	**Questions** What are your views about transferring critically ill patients home to die?
6	Patient and Public Forum	Nurse = 1 Physiotherapist = 1 Lay person = 5	Do you think it is important to transfer critically ill patients home to die? Do you have any worries or concerns about transferring critically ill patients home to die? Which patients would be eligible to be transferred home to die?

Data collection - Interviews

Recruitment – Participants involved in an earlier phase of the larger study and who had experience of transferring a patient home to die, or who had been part of such discussions, were asked about their willingness to be involved in one-to-one telephone interviews aimed at collecting detailed information regarding the decision-making processes of transfer. Interviews took place in September 2012.

Participants - Thirty doctors and nurses indicated they would be willing to be interviewed. After contact and discussion, 15 nurses and 6 consultants were interviewed (Table 2). Interviews lasted between 10 and 55 minutes, with a mean of 27 minutes.

Table 2 Follow on interview participants

Profession/Role	Had transferred patient home to die	Had held discussions about transfer home to die
Nurse	10	5
Consultant	5	1

Procedure – Interviews were conducted over the telephone and audio-recorded with participants' permission. Two interview schedules were developed (Table 3) ; the first for use with HCPs who had been actively involved in a transfer and the second for use with HCPs where only a discussion about transfer home had taken place.

Table 3 Interview schedules for follow on interviews

Interview schedule for telephone interviews with HCPs who had been involved in a transfer home to die	Interview schedule for telephone interviews with HCPs who had been involved in a discussion about transfer home to die
Topic: Dying trajectory and decision making process	**Topic**: Dying trajectory and decision making process
Questions: Can we start with you giving me an overview of the patient? Could you talk me through the decision-making process?	**Questions:** Could you start by talking me through one specific patient about whom or with whom you have had discussions about transferring them home to die.
Topic: Action process – Preparation for transfer	**Topic**: Decision-making
Questions: Could you tell me about preparing for the transfer?	**Questions:** Could you tell me why the patient was not transferred home? What were the deciding factors?
Topic: Action process - transfer	**Topic**: Experience
Questions: Please tell me about the actual transfer.	**Questions:** What would need to be in place for you to consider transferring a patient home to die? Drawing on your experience, what would your advice be to other clinical teams considering a transfer?
Topic: Care at Home	
Questions: Can you tell me about care at home? When did the patient die?	
Topic: Experience	
Drawing on your experience, what would your advice be to other clinical teams considering a transfer? What would support this in practice?	

Data analysis

The detailed process of data analysis for the focus groups (Stage 1) and interviews

(Stage 2) is illustrated in Table 4; this outlines how data was integrated and audited for

rigour.

Table 4. Process of data analysis

Data analysis	Process	Outcome
Stage one – focus groups	All focus group discussions were recorded and transcribed. A preliminary coding list was developed inductively with further iterations of the master code list developed by the research team. Master code list applied to transcripts (ASD). Four transcripts were independently analysed by TLS and MC. Codes were grouped into categories around the study objectives and compared. Preliminary categories were reviewed by the project steering group and research team with further analysis reaching data saturation.	Six transcripts. Preliminary coding list. Master code list of 22 codes. Five categories: Experience, Views, Patient characteristics, Barriers/Facilitators and Concerns.
Stage two: telephone interviews	All recorded telephone interviews were transcribed. A research fellow (AS) commenced an inductive content analysis of interview transcripts under the guidance of two senior researchers (TLS & ASD). Initial coding across the entire data set was completed. A second researcher (ASD) coded three randomly chosen interview transcripts. Both coders worked systematically through the data to achieve data saturation. Data management and coding was facilitated by a QDA software NVivo v10.	21 transcripts indexed and Initial coding list generated. Final master codes list generated. Three categories developed: **Working toward a decision** with five sub categories: non –staff action, staff cognitive work and interaction. **Enacting transfer**, with three sub categories: Leadership, Decision making, and knowledge acquisition. **Post-transfer**, with two subcategories ICU/community interface and reflections.
Stage three: integration	The interview coding list was compared to the focus group coding list and a combined master code list was then agreed and applied deductively to all interview transcripts.	Combined master codes list. Three global themes were generated: **Should we do it? Can we do it? How do we do it?**
Activities to enhance rigour	Development of an audit trail of all meetings held with associated aims and outcomes. Review of individual researchers' coding notes, and notes of Iterative discussion about the coding decisions, discrepancies, and agreed definitions of codes. Discussion of generated codes, categories and final themes with clinical partners and research advisory group.	

Findings

As stated above, data from the focus groups and interviews were integrated leading to the development of three explanatory themes: Should we do it? Can we do it? How do we do it? These themes are now presented together with exemplar quotes.

Transfer home: should we do it?

All participants agreed that the transfer of a critically ill patient home to die should at least be considered when a request was made by a patient or family member.

> *"I think what's one of the messages from this is that there aren't actually massive clinical objections from our point of view for doing this." (FG02)*

Across the focus groups and interviews, both positive and negative views were expressed about transferring patients' home, with nurses being generally more positive about this initiative than doctors.

> *"I have never heard anything negative from any of the nursing staff, they've always been very, very keen to do it." (Consultant, ID12)*

Participants in this study were generally positive and supportive of transfer home to die. However, when beginning to consider how transfer could be achieved, some doctors and nurses indicated that dying within the CRITICAL CARE was preferable to transfer home, with intensive care being perceived as *'a very nice place to die" (FG04).*

Transfer home: can we do it?

Participants reported a range of concerns related to the ability to facilitate transfer and these focussed on consideration of: is the patient suitable for transfer; is there sufficient resource to facilitate transfer; and how would this work with the community services?

Is the patient suitable for transfer?

Consideration of the care needs of the patient at the end of life was a key factor in decision-making regarding potential for transfer home. Participants in both focus groups and interviews identified 'certain types of patients' with high care needs who were not suitable for transfer. These included patients who: were ventilated, had an ischaemic bowel (with continuous diarrhoea), needed regular surgery, had open wounds, a tracheostomy, experienced uncontrollable pain, were receiving high levels of sedation, were unconscious, or assessed as having inadequate mental capacity.

Participants appeared to assess patients' stability and the perceived time to death so that the question posed was: Do we have enough time to organise transfer in view of impending death? The issue of predicting time to death was a key factor in decision making.

> *"He died in the unit and that was a shame, but we tried our best and we had palliative care teams involved who said there's nothing we can do, …the reason he couldn't go because they said he's got more than a few days left to live and therefore we can't take him and I said 'well he might have two weeks to live, but he might only have three or four days', I said 'we can't predict it'…and as it was he actually died about three days after I said that, so he would have been suitable and he never got anywhere near home." (Consultant, ID04)*

Is there sufficient resource to facilitate transfer?

An assessment regarding feasibility of transfer also included consideration of the available unit-based equipment and transfer resource, including the impact of having staff involved in the transfer, off the unit.

"…to have a doctor and a nurse out of the unit for a period of time to get somebody home will make a difference to the staffing on the unit. Now, the nurse that goes home with the patient will be the patient's nurse. That'll probably have less of an effect on the general staffing of the unit but if one of the medical staff disappears that's going to be a quarter of the medical staff at least disappeared." (Consultant, ID11)

How would this work with community services?

Most doctors and nurses were unfamiliar with what was available in their community locality and of the capacity and capability of community staff to care for these patients.

"I think most units would be supportive of the idea [transfer home] but it is the logistics of it… you are often dealing in unique circumstances, with a team that you've not met before." (Consultant, ID14)

When staff were uncertain about community service provision and when time to plan and organise transfer was perceived to be short, then transfer home was unlikely. The outcome of considering if a transfer home was possible was either 'No' or a move to commencing discussions about transfer with other clinical teams.

Transfer home: how do we do it?

Findings indicate that the basis for moving into action to transfer a patient home was informed by a series of critical discussions with key stakeholders including family members, hospital and community colleagues. The outcome of these discussions were critical to implementing transfer. The dominant concerns highlighted in focus groups and interviews were: whether the family could cope with a patient dying at home; the lack of information about the home setting (including access to the property); and the availability of, access to, and capability of community services.

Discussions with the patient or family member about dying at home

It was clear from the interview data that there was an early assessment of the family situation by team members. Doctors and nurses sought to establish patient and family expectations and concerns about transfer home to die. Findings from both focus groups and interviews indicated that the ability of family members to support the person and cope with the person dying at home was vital to achieving transfer. In cases where the patient was the initiator of the idea of transfer, some staff approached the family prior to any agreement with the patient in order to determine

the family's willingness to this. As part of discussions with family, staff spoke with family about what care would be required to care for a patient at home. Staff who had been involved in transfers highlighted that family expectations of transfer home needed to be clarified and that this should be specifically and explicitly discussed prior to any decision to transfer being agreed.

> *"Sometimes families are very keen with the idea 'Oh yes, we want to take him home so then when we say well we need to sit down and talk about it because you're not going to have a nurse there all the time. 'Oh, are we not?' 'No, you're not.' You know, you'll have a telephone number you can contact for out-of-hours if you have any concerns. The nurses will come but their actual input is very minimal, to be honest. It's very much the symptom management, changing the driver…I think the relatives perceive that when their loved ones go home to die that means that what they get here is what they're going to get there." (Nurse, ID13)*

A view clearly expressed in both focus groups and interviews was that patients and families needed to understand the full implications of transfer home.

Discussions with hospital colleagues

Professionals' discussion about transfer home included holding discussions and making arrangements with specific hospital-based personnel: rapid discharge teams; ambulance services and finance managers.

> *"The fast track discharge team…we contacted them and they appeared and have to do a whole lengthy assessment about the patient, the patient's needs, what level of care they require, what equipment they require and then we have to apply, they have to apply directly to the PCT to have the funding agreed to send this patient home, so we did all of that." (Nurse, ID16)*

On engaging with ambulance services, varied experiences were reported ranging from a seamless transfer process to problems with prioritisation for this type of transfer home as opposed to other more routine emergency transfers to other institutions. Organising medical equipment and supplies was pivotal to achieving transfer home and necessitated arrangements for: a bed for the patient at home; patient medication; oxygen for ventilated patients; and continence supplies. This required staff to 'scope out' that situation in order to facilitate transfer:

"Basically what we did was actually look at what we had to do to facilitate it so, we talked through what specialist equipment would be needed so things like a bed… so you know a location exercise of 'is it feasible to have a hospital bed and enough room for the nurses to work around'." (Nurse, ID08)

Ensuring that critical care staff had legal cover to undertake care in peopled' homes was a further issue identified as a potential barrier by interview participants. Medical staff discussed their professional responsibilities with colleagues to ensure that all governance issues were covered including legal cover.

Discussion with community colleagues

Necessary contacts were indicated as: the patient's GP and other support agencies such as district nurses and palliative care teams. A major barrier reported regarding transfer was how willing and able community teams were perceived to be in support of transfer.

"The community services have to be fully involved and also fully signed up to this happening. There's no point in us taking the patient home, dumping the patient home and running away if there's no services in place to take over…that's not fair on the patient or the family. So the

GP and other community services have to be in a position where they

are willing to accept the patient home and are in a position to provide

the appropriate palliative care." (Consultant, ID11)

Discussions with district nurses and community palliative care nurses focussed on home-based support and what the level of support for families would be. Findings indicate that for teams that had never transferred a patient home to die before discussions with community personnel were usually knowledge focussed exploring who needed to be informed or spoken to, what resources were available, what needed to be put in place, and how the process would progress. Once a team had experience of transferring a patient home discussions were less protracted and were usually confirmatory, e.g. agreeing times and resources with linked teams (rapid discharge, ambulance, community).

A final but critical factor in this phase was the identification of a coordinator to lead the transfer home to die. This individual needed the knowledge and skills to liaise across clinical, organisational and geographical boundaries. Interview findings indicated that once a decision to transfer had been agreed, it then fell to an individual/champion to

lead and coordinate the transfer process.   Importantly, the majority of professionals reported nurses to be the natural professional group to lead the process of transfer.

"I'm looking at it very much from the medical side and we have much less to organise than the nurses do, particularly trying to organise community district nursing to go in and support and palliative care teams and Macmillan nurses and things and drugs in the house and oxygen in the house and everything else that has to go with that, all the equipment that has to be taken sometimes…a lot of that's actually sorted out by the nurses." (Consultant, ID04)

Discussion

To our knowledge this is the first study to conduct an in-depth examination of the views, experiences and current practice of doctors and nurses who have considered or have undertaken the transfer of a patient home so that death can happen in the patients, or their families preferred place of death. A key finding of this work is that transferring patients home to die poses significant decision-making challenges to doctors and nurses in CCU. The speed at which decisions need to be made due to time to impending death (hours or days), the views and knowledge-base of CCU staff about

the community-based skills and resources, and the perceived capabilities of the family to cope with a death at home results in such transfers being a rare event.

Similar to findings in previous work, it is clear that whilst doctors and nurses in CCU are positive toward the possibility of transferring patients home to die, the option of transfer is infrequently carried out despite death being anticipated (14). Findings indicate that this option is not 'offered' as part of usual end life care, but as a response to a request from the patient or family.

This is probably not surprising given evidence reporting the challenge that moving a patient from curative interventions to end of life care poses for CCU doctors in particular [19], potentially influenced by the differing dying trajectories identified in CCU's [20]. The reality of implementing a patient led, family focussed process beyond 'the usual' end of life decision-making [21, 22] that includes the organisation of a potentially complex, highly time-dependent transfer to community services, requires a skill set that most critical care doctors and nurses have not yet developed. It merits further consideration whether the frequency of transfer home to die might increase if patients and families in critical care were made aware that in certain circumstances transfer home might be a feasible option as part of end of life care and if flexible

resource could be identified to minimise impact of this initiative on the day to day service provision in CCU.

As reported, early involvement of family in decision-making, with explicit discussions about the logistics of a move home (location, equipment etc.) and what dying at home would involve is essential before any steps are taken to initiate the process of transfer home. Empirical work has indicated the challenging and demanding role that family members face in negotiating and coordinating care during the final phases of life [23, 24, 25]. Families need to be prepared for such a role [26] and how family members could be prepared for the transfer home to die of a critical care patient is an important area for further research.

Similar to recent findings from North America [14], this study has identified that a key feature of a successful transfer is overcoming the knowledge gap around community services and internal discharge processes for patients where the outcome of transfer to the community is death, not recovery or rehabilitation. There is currently no literature that reports on the experiences of community teams when receiving a patient home to die from critical care areas and the resulting demands that this places on the community teams. This lack of knowledge significantly hinders development of

integrated policy and procedures to guide the practice of both secondary and primary care clinical teams when undertaking transfers, and fails to identify the level of support needed by patients and their family members who wish to consider this initiative.

Findings from this qualitative exploratory study clearly indicate that facilitating a transfer home to die from critical care is a complex process requiring multi-agency collaboration and engagement. This paper seeks to provide a point of reference for the future development of local policy and procedures to maximise the potential to affect rapid and effective transfer for those patients who would prefer to die at home through considered planning with co-ordinated leadership.

Study limitations

This study raises important issues related to the process of transfer home to die from critical care. However, there are several study limitations to be acknowledged. As staff were invited to participate in this study, this was a self-selecting sample. This raises the possibility that the issue of transfer home as part of end of life care was important for staff interviewed, or that staff participated due to outstanding issues about this option. Whilst motivations for participation were not explored, all interviewees were able to engage during focus groups or interviews and reflect on their experiences. Due to its

qualitative design and purposive sampling, this study is not directly transferable to other populations or contexts. Its credibility will be confirmed if findings have meaning for other staff involved in end of life care in this setting.

Conclusion

There are evidenced individual [20] and policy [3] drivers promoting high quality care for all adults approaching the end of life, encompassing preferred place of death. Whilst there is evidence of this choice being honoured and delivered for some of the critical care population, it remains debatable whether this will become conventional practice in end of life care in this setting.

We would like to thank Andrew Sibley (AS) for his analytic work on the follow on interviews.

 Declaration of conflict of interests: None

Reference list

1. Department of Health. Gold standards framework: A programme for community palliative care. http://wwwgoldstandardsframwork.nhs.uk (2005, Accessed 21 February 2014).

2. Department of Health. NHS End-of-life care programme progress report summary. http://www.endoflifecare.nhs.uk (2006, Accessed 23 October 13).

3. Department of Health. End of life strategy – providing high quality of care for all adults at end of life. Department of Health, London. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pd. (2008, Accessed 4 January 2014).

4. Tellett L, Davis C. Case 43 Fulfilling a patient's wish to go home from intensive care. European Journal of Palliative Care 2009, 16: 69-70.

5. Kumar G, Obuch S, Vyakarnam P. Withdrawal of intensive care treatment at home— "a good death." Anaesthesia Intensive Care 2009; 37:484-486.

6. Battle E, Bates L, Liderth E, et al. Enabling CRITICAL CARE patients to die at home. Nursing Standard 2014; 29, 5: 46-49.

7. Tellett L, Pyle L, Coombs M. End of life in intensive care: is transfer home an alternative? Intensive and Critical Care Nursing 2012; 28:234-41.

8. Kallel H, Dammak H, Bahoul M, et al A good death: another break in the wall. Intensive Care Medicine 2006; 32: 1915-1916.

9. Boussarsar M and Bouchoucha S. Dying at home: cultural and religious preferences. Intensive Care Medicine 2006; 32: 1917-1918.

10.Mann S, Galler D, Williams P, Frost P. Caring for patients and families at the end of life: withdrawal of intensive care in the patient's home. The New Zealand Medical Journal 2004; 117: 935–943.

11. Huang Y, Huang S, Ko W. Going home to die from surgical intensive care units. Intensive Care Medicine 2009; 35: 810-815.

12. Beuks BC, Nijhof AC, Meertens JHJM, et al . A good death. Intensive Care Medicine 2006; 32:752-753

13. Ryder-Lewis M. Going home from CRITICAL CARE to die: a celebration of life. Nursing in Critical Care 2005; 10: 116-121.

14. Lusardi P, Jodka P, Stambovsky M, et al The going home initiative: getting critical care patients home with hospice. Critical Care Nurse 2011; 31: 46-57.

15. Clinch A, Le B. Withdrawal of mechanical ventilation in the home: a case report and review of the literature. Palliative Medicine 2011; 25:378-381.

16. Kompanje EJO. Should we discharge comatose patient from intensive care to die in their own bed at home after withdrawal of medical ventilation? Intensive Care Medicine 2009; 35: 773-774.

17. Coombs M, Darlington A-S, Long-Sutehall T, Richardson A. An investigation about transferring patients in critical care home to die: experiences, attitudes, population characteristics and practice. Executive Summary of Final Report for Marie Curie Cancer Care funded study, February 2014. Available at e-print@soton.ac.uk

18. Krippendorff, K. (1980). Content analysis. An Introduction to its Methodology. Beverly Hills: Sage

19. Coombs M, Addington-Hall J, Long-Sutehall T. Challenges in transition from intervention to end of life care in intensive care: a qualitative study. International Journal of Nursing Studies 2012; 49: 519-27.

20.Long-Sutehall T. Willis H. Ugboma D. Palmer R. Addington-Hall J. Coombs M. Negotiated dying – how nurses shape withdrawal of treatment in hospital Critical Care units. International Journal of Nursing Studies 2011; 48: 1466-1474.

21. Nosbusch JM, Weiss ME, Bobay KL. An integrated review of the literature on challenges confronting the acute care staff nurse in discharge planning. Journal of Clinical Nursing 2010; 20: 754–774 doi: 10.1111/j.1365-2702.2010.03257.x.

22. Rocker G, Puntillo K, Azoulay E, Nelson J End of life care in the CRITICAL CARE from advanced disease to bereavement. 2010. Oxford University Press, Oxford.

23. Henriksson A, Arestedt K. Exploring factors and caregiver outcomes associated with feelings of preparedness for care giving in family caregivers in palliative care; A correlation, cross-sectional study. Palliative Medicine 2013; 27: 639 – 646.

24. Grande G, Ewing G. Death at home unlikely if informal care givers prefer otherwise: implications for policy: Palliative Medicine 2008; 22: 971 – 972.

25. Caress A, Luker K, Chalmers K, Salmon M. A review of the information and support needs of family carers of patients with chronic obstructive pulmonary disease. Journal of Clinical Nursing 2009; 18: 479 – 491.

26. Hudson P and Payne S. Family carers in palliative care. 2008. Oxford University Press, Oxford.