Transferring patients home to die from ICU: should we do it, can we do it and how do we do it?

Dr Tracy Long-Sutehall PhD, CPsychol, AFBPsS
Associate Professor
Clinical Guidance for Critical Care Staff on Transferring the Critically Ill Patient Home to Die

Transfer home less likely if:
- Patient intubated receiving multiple inotropes
- High level of manual handling/turning needs
- Planned organ donation
- Coroner with police involvement
- Intensive nursing care needs e.g. open wounds, high gastrointestinal losses
- Family lacks capability to support patient dying at home

Stage 1: Assessing potential for transfer home
- The right patient characteristics:
  - Patient with mental capacity expressed wish to go home
  - Patient clinically stable for transfer
- The right time:
  - Sufficient time to organise transfer
  - Transfer planned during core working hours
- The right circumstances:
  - Family supportive/requesting transfer home
  - In-patient clinical team supportive of transfer home to die

Consider:
- Patient/family issues
  - Is patient/family realistic about care package at home?
  - Is patient/family aware of risk of dying during transfer?
  - Has re-admission to hospital been discussed?
  - Has family given consent for ICU follow up call?
- Intensive care issues
  - Who will take the lead in transfer arrangements?
  - Who will accompany the patient home (staff and relatives)?
  - How are any treatments to be withdrawn, by whom and when?
  - Can the unit manage without the staff involved in the transfer?
  - Are there funding implications?

Community issues
- Will GP support transfer of patient home to die?
- Is care package at home in place?
- How will patient symptoms be managed at home?
- Who will sign the death certificate?
- Has there been discussion about how family can participate in care at home?
- Transfer issues
  - Has time been built in for changes to care before transfer e.g. conversion to syringe driver?
  - Do transfer staff know what to do if patient dies during transfer?
  - Are there any medico-legal/indemnity issues for healthcare staff involved in the transfer?
  - Are arrangements in place to return ICU staff and equipment to the hospital?

Home issues
- Is home suitable for transfer and care e.g. stairs, toilet, bedroom?

Potential contact personnel:
- General Practitioner
- Hospital palliative care team
- Hospital rapid discharge team
- Community nursing services
- Community palliative care team
- Ambulance services
- ICU technicians
- Coroner
- Social worker
- Pharmacist

Equipment and supplies:
- Specialised bed/mattress
- Oxygen and respiratory support
- Continence supplies
- Syringe driver
- Medications and prescriptions
- Dressings

Documentation:
- ICU discharge letter
- DNACPR form
- Expected death form
- Rapid discharge forms

Stage 2: Preparing for transfer

Stage 3: During the transfer

Stage 4: On arrival at home
- Handover to community team (incl. GP, community nursing staff) as arranged
- Ensure family aware of who and when community doctors and nurses will visit
- Reinforce information to family: signs of deterioration and impending death and who to contact for support or in the event of patient death

Stage 5: Follow up after the transfer
- Follow local unit policy for transfer of critically ill patient

NB: Families can say ‘No’ to transfer at any time.

If transfer not possible then:
- Discuss end of life management plan with family
- Consider best place of care e.g. remain on ICU or alternative care setting
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.
Research design

Phase 1
- Literature review
- Focus groups
- National survey
- Post survey telephone interviews

Phase 2
- Audit

Phase 3
- Stakeholder engagement
Phase 1: Should we do it?

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.

Questions
What are your views about transferring critically ill patients home?
Do you think it is important to transfer critically ill patients home?
When would you transfer a critically ill patient home?
When would you NOT transfer a critically ill patient home?
What is needed to offer to transfer a critically ill patient home?
Do you think it is feasible to transfer a critically ill patient home?

Six focus groups with 49 participants
Lay members = 5
Physio = 1
Nurses = 28
Doctors = 15
On-line Survey

Sent to lead consultant & lead nurse in 409 Critical Care units in UK

756 HCP’s received an invitation to participate 180 HCPs (response rate 24%)
Phase 1: Survey

### Table 1. Participant discipline

<table>
<thead>
<tr>
<th>Discipline</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurses</td>
<td>97</td>
<td>54%</td>
</tr>
<tr>
<td>Doctors</td>
<td>71</td>
<td>39%</td>
</tr>
<tr>
<td>Missing/Unclear</td>
<td>13</td>
<td>7%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>181</td>
<td></td>
</tr>
</tbody>
</table>

### Table 2. Participant Unit

<table>
<thead>
<tr>
<th>Unit</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>HDU</td>
<td>8</td>
<td>4%</td>
</tr>
<tr>
<td>ITU</td>
<td>27</td>
<td>15%</td>
</tr>
<tr>
<td>HDU/ITU</td>
<td>121</td>
<td>67%</td>
</tr>
<tr>
<td>Other</td>
<td>23</td>
<td>13%</td>
</tr>
<tr>
<td>Missing</td>
<td>2</td>
<td>1%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>181</td>
<td></td>
</tr>
</tbody>
</table>

### Table 3. Participant Country

<table>
<thead>
<tr>
<th>Country</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>141</td>
<td>78%</td>
</tr>
<tr>
<td>Scotland</td>
<td>14</td>
<td>8%</td>
</tr>
<tr>
<td>Wales</td>
<td>9</td>
<td>5%</td>
</tr>
<tr>
<td>N. Ireland</td>
<td>12</td>
<td>7%</td>
</tr>
<tr>
<td>Missing</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>178</td>
<td></td>
</tr>
</tbody>
</table>
### Views: Focus groups

“I think that one of the messages from this is that there aren’t actually massive clinical objections from our point of view for doing this, our reservations come from what actually happens out there to our patients when we have given them back to the community” (FG02)

### Barriers

- Critical care culture
- Identifying suitable patients
- Managing family expectations of a home death

*Lack of knowledge about:*
- Community package
- Home environment

### Facilitators

- Time
- Support
- Guidelines
Views: survey

- Transferring critically ill patients home to die is important because patients should be able to die at home if that is their **preferred place of death** (82% agree)

- Transferring critically ill patients home to die is a **feasible option** in critical care (61% agree)

- It is **unethical to prolong** a patient’s life so they can be transferred home to die (36% agree)

- Transferring patients home to die is **not worth the risk** of dying in the ambulance or having a really bad death at home (13% agree)
66 (36%) participants indicated they had experience of transfer home to die in the last three years

<table>
<thead>
<tr>
<th>Experience of transfer home to die</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 patient home to die</td>
<td>20</td>
</tr>
<tr>
<td>2 patients home to die</td>
<td>15</td>
</tr>
<tr>
<td>3 patients home to die</td>
<td>12</td>
</tr>
<tr>
<td>4 patients home to die</td>
<td>1</td>
</tr>
<tr>
<td>5 patients home to die</td>
<td>12</td>
</tr>
<tr>
<td>More than 6 patients home to die</td>
<td>6</td>
</tr>
</tbody>
</table>

28 (16%) had had discussions about transfer home to die

<table>
<thead>
<tr>
<th>Discussions about transfer home to die</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 patient discussed</td>
<td>6</td>
</tr>
<tr>
<td>2 patient discussed</td>
<td>14</td>
</tr>
<tr>
<td>3 patient discussed</td>
<td>4</td>
</tr>
<tr>
<td>4 patient discussed</td>
<td>1</td>
</tr>
</tbody>
</table>
## Patient Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>is unconscious</td>
<td>101</td>
<td>63</td>
</tr>
<tr>
<td>is conscious</td>
<td>166</td>
<td>0</td>
</tr>
<tr>
<td>is unstable</td>
<td>63</td>
<td>102</td>
</tr>
<tr>
<td>is stable</td>
<td>163</td>
<td>2</td>
</tr>
<tr>
<td><strong>who is ventilated via an endotracheal tube</strong></td>
<td>52</td>
<td>113</td>
</tr>
<tr>
<td>who is ventilated via tracheostomy</td>
<td>96</td>
<td>70</td>
</tr>
<tr>
<td>who is receiving non-invasive ventilation</td>
<td>126</td>
<td>41</td>
</tr>
<tr>
<td>is self-ventilating breathing oxygen</td>
<td>159</td>
<td>8</td>
</tr>
<tr>
<td>who is self-ventilating breathing air</td>
<td>167</td>
<td>0</td>
</tr>
<tr>
<td>needs cardiovascular support e.g. inotropes</td>
<td>57</td>
<td>109</td>
</tr>
<tr>
<td>has intense nursing needs e.g. frequent turning and washing</td>
<td>128</td>
<td>37</td>
</tr>
<tr>
<td>has high level emotional needs</td>
<td>146</td>
<td>20</td>
</tr>
<tr>
<td>has relatives with high level emotional needs</td>
<td>131</td>
<td>35</td>
</tr>
<tr>
<td>needs regular medication for symptom management (e.g. pain, nausea)</td>
<td>150</td>
<td>16</td>
</tr>
<tr>
<td>lives outside local catchment area</td>
<td>135</td>
<td>31</td>
</tr>
</tbody>
</table>
Main findings focus groups and survey:

Transferring critically ill patients home to die:

- HCP’s supportive of idea
- Transfer home is not common, but has been done
- Transfer home is perceived to be a complex process
- Patient characteristics are key factors in decision-making, e.g. transferring unstable or ventilated patients home is unlikely
- Perceived barriers exist: emphasis on community care
- Concerns exist: emphasis on coping of relatives
- Feeling that Guidelines would facilitate the development of this initiative as a feasible service to patients
An Investigation about Transferring Patients in Critical Care Home to Die

Phase 2: Audit
Phase 1 review

- Retrospective audit patients died 2011
  Total n=7844 notes, from 7 units
- Level 1 exclusion:
  - cardiac arrest
  - sudden death
  Excluded N = 62 (14.7%)

Phase 2 review

- Review for level 2 exclusion: 'Unstable'
  Patient observations show significant variability/deterioration or introduction of new therapy as result of patient deterioration
  Excluded N = 225 (53.3%)

Phase 3 review

- Review for level 3 exclusion: environmental/care factors
  Coroners cases
  Complex family issues
  Intense manual handling
  High Gastrointestinal losses
  Excluded N=35 (8.3%)

Total deaths = 422 (5%)
Total exclusion = 322 (77%)
Potential for transfer

- N=100; 23.7%
- 44% women
- Mean age 70.4 years
- The majority of patients had been diagnosed with respiratory (41%), neurological (19%) or cardiac disease (19%).
- Mean time between discussion about withdrawal time of death: 36.4 hours.
- Comparative analysis indicated that patients included were more likely to be treated in HDU than ITU.
Post survey interviews key points

Assessment for transfer

- Knowledge seeking activities within service re feasibility: funding, resource, logistics and time.
- Discussion with family

Operationalising transfer

- Identifying a leader
- Discussions with hospital colleagues (palliative care/rapid discharge teams)
- Discussion with community colleagues (GP/District team)
So…?

Should we do it?

- Offering choice - 20% of patients from the ICU, s in this study could potentially have been transferred home to die.
- Health Care Professionals in both acute and public health settings are largely supportive of transferring patients from ICU home to die.

Could we do it?

- Transfer home is currently not common but has been successfully achieved.
- Patients who were eligible for transfer had relatively low levels of care requirements (minimal respiratory or ventilator support; more likely to be treated in a HDU).

How do we do it?

- Consider this end of life option.
- Appoint a unit coordinator.
- Access support from: rapid discharge team/palliative care discharge team.
- Establishment of local guidelines developed with community teams would facilitate transfer home to die.
Clinical Guidance for Critical Care Staff on Transferring the Critically Ill Patient Home to Die

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The ‘right’ patient characteristics:
- Patient with mental capacity expressed wish to go home
- Patient clinically stable for transfer

The ‘right’ time:
- Sufficient time to organise transfer
- Transfer planned during core working hours

The ‘right’ circumstances:
- Family supportive/requesting transfer home
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Consider:
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  - Is patient/family realistic about care package at home?
  - Is patient/family aware of risk of dying during transfer?
  - Has readmission to hospital been discussed?
  - Has family given consent for ICU follow up call?

- Intensive care issues
  - Who will take the lead in transfer arrangements?
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- Home issues
  - Is home suitable for transfer and care e.g. stairs, toilet, bedroom?

Stage 3: During the transfer

Follow local policy for transfer of critically ill patient

Stage 4: On arrival at home

Follow care plan as discussed in hospital (including any treatment withdrawal)
- Handover to community team (incl. GP, Community Nursing staff) as arranged
- Ensure family aware of who and when community doctors and nurses will visit
- Reinforce information to family: signs of deterioration and impending death and who to contact for support or in the event of patient death

Stage 5: Follow up after the transfer

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Transfer home less likely if:
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- Medications and prescriptions
- Dressings

Documentation:
- ICU discharge letter
- DNACPR form
- Expected death form
- Rapid discharge forms

NB: Families can say ‘No’ to transfer at any time
**Link to final report**
http://www.southampton.ac.uk/healthsciences/research/projects/an_investigation_about_transferring_patients_in_critical_care_home.page

**Publications**

Coombs M, Darlington AS, Pattison N, Long-Sutehall T, Richardson A. (accepted BMJ supportive and palliative care) Transferring patient’s home to die: what is the potential population in UK critical care units?


Coombs M, Long-Sutehall T, Darlington AS, Richardson A. (2014) A qualitative study exploring transfer of patients home to die from critical care: should we do it, can we do it and how do we do it? Palliative Medicine. DOI: 10.1177/0269216314560208
An evaluation of the provision of bereavement follow-up services in intensive care units across the UK: a national survey

Researchers from the UK (Dr Tracy Long-Sutehall), Australia (Dr Marion Mitchell) and New Zealand (Professor Maureen Coombs) are carrying out an evaluation of the provision of bereavement follow-up services in intensive care units across these three countries. New Zealand and Australian surveys are almost complete and the next step is to seek expression of interest from UK intensive care units.

We would like to send an email invitation including a link to the online survey to individuals who can provide information about the provision of bereavement follow up services in their unit. We are also interested in scoping provision, so even if your unit does not provide a service, we would like to hear from you.

If you, or the senior nurse for your unit, would like to be included in this survey, or hear more about it, please e-mail Dr Tracy Long-Sutehall at T.Long@soton.ac.uk.
Questions