Transferring home to die from critical care units: a scoping review of international practices

Abstract

**Purpose**. To identify and characterise the international practices of transferring a dying patient home to die from critical care units.

**Materials and methods:** A systematic scoping review following the Joanne Briggs Institute methodology was applied searching fifteen data sources to identify papers published in English and Chinese from 1970-2019.

**Results:** Of the 28 papers meeting eligibility criteria 19 were published in the West and seven in China. The number of patients being transferred home to die was larger in China (74/184 - 96/159) than in the West (1 - 7). Clinical characteristics of patients transferred included: consciousness, with or without intubation and ventilation, and clinical stability. Reported key barriers to transfer included: Lack of evidence guiding transfer practice, the CCU environment and culture, Practical and logistical factors and Family members expectations and reactions. Key facilitators of transfer were reported as: Engagement with the multidisciplinary team and Personal patient and family wishes.

**Conclusions:** Transferring patients home to die from critical care is a complex practice varying significantly across countries. Further research to address current knowledge gaps is important to inform policy and practice.

**Keywords:** critical care; discharge; home death; scoping review; transfer; treatment withdrawal

Introduction

Place of death is an important topic in end-of-life (EoL) decision-making. Globally, dying in a preferred place, which is often home, is viewed by many as a good death [1-5]. Evidence shows that most people worldwide (no data from mainland China), including patients, and caregivers state a preference to die at home rather than in hospital or other institutions [6]. Home death is reported to be more peaceful for the patient and to positively influence the bereavement process for families [7].

Globally there is an incongruence between preferred and actual place of death. In the West, only 22 - 57 per cent of people are reported to die at home [8-10]. However, in mainland China, the number of home deaths is estimated to be 82 – 92 per cent of deaths [11-13]. Factors influencing decision-making associated with dying at home in the West include: patients’ low functional status, their reported preferences, the intensity of home care, living with relatives, and the availability of extended family support [14]. The perceived level of family support and health care input is also reported as reasons for change of personal preference [6, 15-17], with a shift away from home to institutions [16, 18-20] where family support is not available and/ or health care provision is not in place. However, in mainland China decisions about home deaths are influenced by factors including: cultural, religious, and spiritual meaning of the home as a place of death [21].

For patients in critical care units (CCUs) including intensive care units (ICUs), intensive therapy units (ITUs), and high dependency units (HDUs) [22, 23] (from here on referred to as CCUs), going home to die is reported as a preference for many [24]. This suggests that transferring home to die (THtD) from CCUs may be a meaningful option for patients and their family members. However, THtD is a complex process presenting challenges [25] as approximately one fifth of patients die in ICUs after admission [26-30] Despite this figure evidence suggests that some patients who die in CCUs could potentially be transferred home to die [31].

THtD from CCUs is a particular type of transfer and all such transfers are complex [32, 33] as the acutely ill patient is at an increased risk of haemodynamic instability during a transfer and the physical process of transfer may contribute to deterioration [32]. Key drivers for health care professionals (HCPs) in considering THtD include: maintaining the continuity of medical care and ensuring key elements of safe transfer are implemented. These elements include: a robust decision making process underpinning planning for THtD; pre-transfer stabilisation and preparation; selection of the appropriate mode of transfer (i.e., land transport or air transport); personnel accompanying the patient; equipment and monitoring required during the transfer; and documentation and handover of the patient to the family [34]. Despite a number of studies investigating preferences around place of death [14, 15, 35, 36] and EoL decision-making in critical care [37-40] there is a paucity of evidence on the specific practice of THtD from CCUs [41]. This scoping review addresses this current gap in knowledge by identifying and characterising the current practice of transferring a dying patient home to die from hospital CCUs.

Methods

## Review question

This paper presents a scoping review that aims to answer the question*: What is known in the international literature about the practice of transferring patients home to die from hospital critical care units?*

## Review objectives

1. To identify which countries, report the practice of THtD
2. To establish the characteristics of patients THtD where this practice is undertaken
3. To outline the reported barriers and facilitators underpinning THtD practice

## Review methodology

A scoping review methodology [42] applying the Joanna Briggs Institute (JBI) method [43-45] was undertaken in association with the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist [46].

## Study eligibility

In accordance with the JBI Participants Concept Context (PCC) framework [45] the following criteria were used to determine eligibility for inclusion for this review: a) Participants: adult patients (age: 18 years and older) who were critically ill or terminally ill; b) Concept: papers reporting information about the practice of THtD, including: number of patients transferred over a specified period of time, individuals involved in the transfer decision-making process, and barriers to, and facilitators of THtD; c) Context: transferring home from CCUs in any countries or regions; d) Sources: no restrictions were placed on data sources or study design; e) Date range: as debates about place of death are recorded in literature from 1970 papers published from1970 to 2019 were eligible for inclusion.

## Search strategy

Search terms (Table 1) were entered: MEDLINE (EBSCO), CINAHL (Plus with Full Text), EMBASE, AMED, PsychINFO, Web of Science (core collection), Scopus, NICE, The British Library, Open Grey, The Cochrane library, Google Scholar, CNKI (China National Knowledge Infrastructure), Wan Fang, and Baidu Wenku.

Table 1 Search terms

|  |  |
| --- | --- |
| PCC framework | Search terms selected |
| Participants | dying patient, terminally ill patient, terminally ill, terminal care, withdrawal of treatment, withdrawal of life sustaining treatment, treatment withdrawal, end of life, end of life care |
| Concept | patient transfer, transfer home, transfer, transfer home to die, transfer patient, patient discharge, discharge, discharge home, patient handoff, discharge planning, continuity of care, transitional care |
| Context | home death, dying at home, die at home, death at home, home palliative care, home care service, place of death, site of death, dying location, critical care unit, critical care, intensive care unit, critical care setting, CCU, ICU |

## Outcome of searches

The outcome of searches including paper selection is presented in the PRISMA-ScR flow chart in Figure 1. Papers written in English and Chinese were included as the lead author (YL) is bilingual. Searches generated 239 records which were imported into reference manager software Endnote X7.2 (Clarivate Analytics, PA, USA)). Following duplicate removal, the title and abstract of 163 records were screened against the inclusion criteria by YL and selected articles were discussed with MM and TLS. Screening excluded 122 papers and 41 papers underwent full-text review. Following review of the reference lists of the final 41 paper identified a further seven papers also underwent full paper review. Of the 48 papers reviewed in full, 28 papers met the inclusion criteria and were included in the final review.

In line with scoping reviews assessing the quality of papers is not mandatory and was not undertaken for this review [45, 46]. However, this review took a critical stance to the retrieved literature by appraising the overall methodological limitations of papers included.

**172** records identified through bibliographic databases:

MEDLINE: 19

CINAHL: 6

PsycINFO: 28

EmBASE: 45

AMED: 2

Web of Science: 4

Scopus: 22

Google Scholar: 40

CNKI: 3

Wan Fang: 3

**67** additional records identified through grey literature sources:

NICE: 41

Open Grey: 3

The British Library: 0

The Cochrane Library: 0

Baidu Wenku: 23

**163** records screened after duplicates removed

**41** full-text papers assessed for eligibility

**28** papers included

**122** records excluded

**20** papers excluded because:

* Non-adult population: 1
* No information on the review concept of transfer: 19

**Identification**

**Screening**

**Eligibility**

**Identified**

**7** additional full-text papers retrieved from reference lists

Figure 1 PRISMA- ScR flow chart of evidence source selection

## Data extraction and charting

A data extraction template was developed (Table 2) which included: authors, year, and title, country of origin, aims, study participants, patient characteristics, design/ methods, number of patients THtD, and participants in transfer decision-making. Patient characteristics comprised: gender, age, ethnicity, cause of death, capacity of decision-making, life-sustaining treatment, time to death following transfer.

Table 2 Summary table of retrieved papers (n=28)

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Author, Year, Title, [Reference ID] | Country of origin | Aims | Study participants | Patient characteristics\* | Design/  Methods | Number of patients THtD | Participants in transfer decision-making |
| Xu, Zhang, 2001, The prevalence and factors of self-discharge in ICU **[47]** | Mainland China | Unspecified | Patients who were classified as “self-discharge” or who died in the ICU (n=159) | M: n=57, F: n=39; Cause of death: traumatic brain injury (n=14), stroke (n=33), tumour (n=7), COPD (n=7), MODS (n=15), others (n=20) | Retrospective chart review | 60% (96/159, in two years) of dying patients | - |
| Mann, Galler, 2004, Caring for patients and families at the end of life: withdrawal of intensive care in the patient's home **[48]** | New Zealand | To describe our experience of transporting 17 intensive care patients home to die. | M: n=8, F: n=9, Age: 51  (19-83), Ethnicity: Maori (who are the indigenous people of New Zealand) or Polynesian; Cause of death: brain injury (n=4); community cardiac arrest (n=1); intra-cerebral haemorrhage (n=3); brain death (n=1); multi-organ failure(n=2); respiratory failure(n=1), complications following surgery(n=2); on both ventilation and inotropes (n=9), only on ventilation (n=6), only on inotropes (n=1), neither (n=1); Time to death: 0.1-72 hours | | CCR | N=17 (1996-2002) | Family, ICU medical staff, district nurses, GPs, palliative care practitioner or hospice service |
| Ryder-Lewis, 2005, Going home from ICU to die: a celebration of life **[49]** | New Zealand | Unspecified | Maori and Pacific Island families | | Service description | N=14 patients (over four years) | Family, nursing staff and intensivist, community HCPs, palliative health care teams, ambulance officers, the flight retrieval service, and the coroner |
| Jackson, 2006, Withdrawal of care at home: transfer from the ICU to provide end of life care at home **[50]** | New Zealand | Unspecified | Maori (66%), Pakenham (20%), Samoan (7%) and Pacific Island (7%) | | CCR (conference abstract) | N=15 (since 1999) | Family, ICU HCPs |
| Kallel, Dammak, 2006, A good death: another break in the wall **[51]** | Tunisia | Unspecified | M, 76, Muslim, COPD, arterial hypertension, congestive heart failure and diffuse cerebral haemorrhage, deep coma, intubated, ventilation and inotropes, a few minutes | | CCR | N=1 | Family (wife and two sons), ICU doctor and nurses |
| Boussarsar and Bouchoucha, 2006, Dying at home: cultural and religious preferences **[52]** | Tunisia | Unspecified | Ethnicity: Muslims society; Cause of death: late septic shock state and multi-organ failure; respiratory and hemodynamic life support | | Discussion paper | Nearly 10% of deaths per year  (10/102 in 2005) | Family, ICU medical staff |
| Beuks, Nijhof, 2006, A good death **[53]** | Netherlands | Unspecified | F,56, non-Hodgkin lymphoma, conscious, extubated in ICU, several days  F, 58, probably tumour, conscious, extubated in ICU, one day | | CCR | N=2 | Patients, families, ICU nursing staff and doctors |
| Crighton, Coyne, 2008, Transitioning to end-of-life care in the intensive care unit: a case of unifying divergent desires **[54]** | USA | (1) To gain insight into the multi-dimensional aspects of patient’s, family’s, and medical providers’ approaches to EoL care and (2) To consider how conflicting goals of treatment influence the transition to EoL care in the ICU | F, 62, glioblastoma multiform, unresponsive, no life-sustaining treatment, Time to death: five months | | Ethnographic case study | N=1 | Family, ICU physician, palliative care consultant |
| Kumar, Obuch, 2009, Withdrawal of intensive care treatment at home - 'a good death' **[55]** | UK | Unspecified | F, 71, multi-organ failure, conscious, inotropes, 90 minutes | | CCR | N=1 | Patient, relatives, ICU doctors and nurses, GP and district nurse, the palliative care team, clinical government bodies |
| Tellett and Davis, 2009, Case 43 Fulfilling a patient's wish to go home from intensive care **[56]** | UK | Unspecified | M, 58, Ebstein anomaly and multi-organ failure, conscious, inotrope and hemofiltration, three days | | CCR | N=1 | Patient, family (wife), cardiac intensive care unit nurse consultant, community, clinical nurse specialist in adult congenital heart disease |
| Kompanje, 2009, Should we discharge comatose patients from intensive care to die in their own bed at home after withdrawal of mechanical ventilation? **[57]** | Netherlands | Unspecified | - | | Discussion paper | - | - |
| Huang, Huang, 2009, Going home to die from surgical intensive care units **[58]** | Taiwan China | To better understand events related to going home to die from the ICU, with the hope that this information might improve the palliative care of ICU patients | M: n=227, F: n=119; Age: 62.6±16.2; Ethnicity: 98% Han; ventilation; vasopressive medication; Time to death: within minutes to hours | | Retrospective observational study | N=346 (around 25%, in four years) | Family, the attendant physician, nurse |
| Lusardi, Jodka, 2011, The going home initiative: getting critical care patients home with hospice **[59]** | USA | Unspecified | M: n=5, F: n=2, Age: 66  (55-74), Cause of death: cerebrovascular accident, respiratory failure (n=1); respiratory failure (n=4); hypotension (n=1); pancreatitis, chronic; renal failure (n=1); no life-sustaining treatment, Time to death: 8 - 48 hours | | CCR/  Service description | N=7 (2009-2011) | Patients, families, ICU nurses, the clinical nurse specialist, and the intensivist, primary care physician, local hospice staff, the case manager, an interfaith chaplain,  a social worker |
| Clinch and Le, 2011, Withdrawal of mechanical ventilation in the home: a case report and review of the literature **[60]** | Australia | Unspecified | M, 71, meningoencephalitis and pneumonia, conscious, ventilation, 4.5 hours | | CCR | N=1 | Patient, family, ICU clinicians, GP, local domiciliary palliative care, hospital palliative care physician, respiratory clinical nurse, hospital management, registrar |
| Sheng, Liu, 2012, Investigation on decision making of ICU dying patients and their families **[61]** | Mainland China | To understand the participation of patients and their families in decision-making in ICU and analyse the types and reasons of forgoing ICU treatment | Patients who were not cured or died in the ICU of two hospitals (n=211, in one year) | - (no characteristics of patients discharged) | Retrospective chart review | 40% (74/184) of all dying patients (calculated based on available data) | Family members (adult children and spouse), physicians |
| Tellett, Pyle, 2012, End of life in intensive care: Is transfer home an alternative? **[62]** | UK | This paper seeks to challenge assumptions and practices about the options for transferring the critically ill patient home at end of life | The patient’s wife | M; 58; Ebstein anomaly; conscious; haemoﬁltration and dopamine support which were stopped before transfer; three days. | Collaborative writing between authors and participant | N=1 | The patient, family (wife, two children), intensive care team, palliative care team, different clinical teams involved in the treatment (congenital cardiac, heart failure, respiratory, electrophysiology, hepatology; and renal) |
| Campbell, 2013, Opinion piece: Honouring the wishes of a dying patient: From intensive care to home with palliative care **[63]** | Australia | Unspecified | M, 64, Urosepsis and multi-organ failure, conscious, no ventilation and inotropes, a few days | | CCR | N=1 | Patient, family, ICU medical team, a clinical nurse consultant from palliative care |
| Nielsen, 2013, Getting critical care patients home for end-of-life care **[64]** | Denmark | Unspecified | Age: 68-84; Cause of death: end-stage lung disease, cancer, surgical complications, conscious; Time to death: a few hours- four days | | CCR (conference abstract) | N=7 (in two years) | Patient, family, ICU HCPs, primary care physician and nurse |
| Zhao, Zhang, 2014, Current situation and associated factors of withdrawing or withholding life support to patients in an intensive care unit of cancer center in China **[65]** | Mainland China | To investigate the current situation and analyse the associated factors of withdrawing or withholding life support in ICU of the authors’ cancer centre | ICU patients (n=322, in two years) | - | Retrospective observational study | 52% (64/124) of all dying patients (calculated based on available data) | Family members (adult children and spouse), physicians |
| Battle, Bates, 2014, Enabling ICU patients to die at home **[66]** | UK | Unspecified | F, 68, COPD, conscious, tracheostomy and ventilation, a few minutes;  F, 71, ovarian adenocarcinoma, conscious, ventilation, 3.5 hours | | CCR | N=2 | Patient, family, a friend, ICU doctors and nurses, consultant;  ICU nurses, healthcare assistant, district nurse liaison team, local bereavement team, hospice staff, end of life care programme manager, the ward manager |
| Coombs, Long-Sutehall, 2014, Doctors' and nurses' views and experience of transferring patients from critical care home to die: a qualitative exploratory study **[25]** | UK | To examine current experiences of, practices in and views towards transferring patients in critical care settings home to die | N=49 HCPs: doctors and nurses from four ICUs, GPs and community nurses;  members of a Patient and Public Forum; 15 nurses and 6 consultants from CCUs | - | Exploratory two-stage qualitative study: focus groups, follow up interviews | - | Patient, family members, CCU staff, community colleagues: GP, district nurses, palliative care teams, specific hospital-based personnel, rapid discharge teams, ambulance services and finance managers |
| Darlington, Long-Sutehall, 2015, A national survey exploring views and experience of health professionals about transferring patients from critical care home to die **[67]** | UK | To examine (1) HCPs’ experience of transferring patients home to die from critical care, (2) HCPs’ views about transfer and (3) characteristics of patients, HCPs would hypothetically consider transfer | N=180 lead doctors and senior nurses working in 409 CCUs across the UK | - | National online survey | - | - |
| Coombs, Darlington, 2015, Transferring critically ill patients home to die: developing a clinical guidance document **[68]** | UK | To develop clinical guidance on the practice of transferring patients home to die for doctors and nurses in critical care | Doctors and nurses from secondary (n=57) and primary care trusts or palliative care teams (n=18), allied health professionals (n= 4), service users (n= 6) | - | Mixed methods involving consensus methodology and nominal group technique | - | Patient, family, ICU staff, community-based teams, GP, Macmillan/hospice visits, bereavement services, in-hospital teams (including home team, rapid discharge) |
| Xie, Yu, 2015, Feelings of withdrawal of life sustaining therapy in families of ICU dying patients **[69]** | Mainland China | To understand family members’ experience of forgoing treatment for patients at end of life stage in ICU in multi-ethnic regions of Xinjiang | Family members of patients with decision to WLST in ICU (n=15) | - | Phenomenological study | - | Family members, ICU physician |
| Liu, Zhou, 2016, Influencing factors of clinical decision of family members of end of life patients in intensive care unit **[70]** | Mainland China | To understand the factors associated with family members’ decisions for terminally patients in ICU | Family members of ICU patients (n=10) | - | Phenomenological study | - | Family members |
| Liu and Zhu, 2016, Qualitative research on refusing to give up treatment of family members for ICU end-of-life patients **[71]** | Mainland China | To understand the reasons that families refused to forgo treatment for ICU terminally ill patients | Family members of ICU patients (n=10) | - | Phenomenological study | - | Family members, ICU physician |
| Hutchinson and Van Wissen, 2017, Home to die from the intensive care unit: a qualitative descriptive study of the family’s experience **[72]** | New Zealand | To gain insight into family members’ experiences when an adult ICU patient is taken home to die | Four family members | Conscious (n=2); tracheostomy (n=1) | Qualitative descriptive study | N=4 (in 14 months) | Patient, family, ICU doctors and nurses, community care services |
| Coombs, Darlington, 2017, Transferring patients home to die: what is the potential population in UK critical care units? **[31]** | UK | To determine the size and characteristics of the critical care population who could potentially be transferred home to die | All patients admitted to the ICU/HDUs during 1 January 2011 to 31 December 2011 and who subsequently died in the ICU/HDU or within 5 days of discharge from these units (n=7844) | - | Retrospective cohort study | - | - |

\*Not all items were available in every paper; M=Male, F=Female; COPD= Chronic Obstructive Pulmonary Disease, MODS=Multiple Organ Dysfunction Syndrome;

CCR=Clinical case report; ‘-’ indicates no available data or not applicable item

Results

To meet objective 1: *to identify which countries, report the practice of THtD* and 2: *to establish the characteristics of patients THtD where this practice is undertaken*, data from the retrieved studies were charted under the headings: study design, country of origin, number of patients THtD, patient characteristics, and study participants. Review objective 3: *to outline the reported barriers and facilitators underpinning THtD practice,* was addressed in a synthesised narrative and illustrated in Table 3.

## Study design

Eleven papers were reported as clinical case reports [48, 50, 51, 53, 55, 56, 59, 60, 63, 64, 66], six papers reported qualitative studies [25, 54, 69-72] and five carried out retrospective chart reviews or observational studies [31, 47, 58, 61, 65]. Diverse designs and methods by the remaining papers included: one service description [49], two discussion papers [52, 57], one national online survey [67], one referred to as collaborative writing [62], and one mixed methods study involving consensus methodology and nominal group technique [68].

*Country of origin*

Of the retrieved 28 papers, most papers (n=19) were published in the West with a predominance in the UK (n=8) [25, 31, 55, 56, 62, 66-68]. Seven papers offered limited information about THtD in ICUs following withdrawing/withholding life sustaining treatment (WLST) in China with six from mainland China [47, 61, 65, 69-71] and one paper from Taiwan [58].

*Number of patients THtD*

The number of patients THtD from CCUs in the West ranged from 1- 7 [53-56, 59, 60, 62-64, 66, 72], with most reporting the transfer of one or two patients [53-56, 60, 62, 63, 66], except New Zealand where 14- 17 patients were THtD over a 4-7 year time period [48-50]. THtD was most common in Tunisia [52] and China [47, 58, 61, 65], particularly mainland China where 40% (74/184) - 60% (96/159) of dying patients were THtD [47, 61, 65].

*Patient characteristics*

Information about patient characteristic was available in 18 studies [47-56, 58-60, 62-64, 66, 72]. More male than female patients (302 males, 175 females), aged between 19 and 83 years were THtD from CCUs.

Three categories of patients THtD were identified: conscious or unconscious, intubated and ventilated or not, and stable or instable, indicating that various criteria of patients who could be transferred home were applied in practice worldwide. It was usually conscious patients who were transferred home to die in the West [53, 55, 56, 60, 63, 66] as unconscious patients were not considered suitable for a transfer by HCPs [25, 57, 68]. However, two CCUs reported transfer home of unconscious patients [51, 54]. Patients who did not require intubation and ventilation were more often transferred home [53, 54, 56, 59, 62, 63] than patients who were intubated and/or ventilated. Differences in decision making regarding transfer of extubated patients were reported with intubated patients being assessed as not suitable for transfer [25, 59, 67, 68] and in other units being assessed as suitable [48, 49, 51, 58, 60, 66, 72]. Similarly, differences in decision making regarding unstable patients, such as those with low blood pressure, or on inotropes and who were assessed as potentially at risk of dying on the way home, or soon after reaching home, were not considered suitable to be transferred home [59, 67], while some extremely unstable patients were transferred home to die in other settings [48, 51, 55].

*Study participants*

The practice of THtD from CCUs was investigated mainly from the perspective of HCPs (n=20) in the West, and only two papers explored the experiences of family members in transfer process in the countries outside China [62, 72]. Three described families’ experiences of decision-making focusing on WLST for CCU patients in China [69-71].

## Barriers and facilitators

Objective 3 is addressed in the following synthesis of data indicating barriers and facilitators to THtD from CCUs mainly derived from practice reported in the West as this topic has received very little attention in countries such as China [47, 58, 61, 65, 69-71]. Table 3 lists the overarching barriers and facilitators with key detail provided in the synthesis.

Table 3 Barriers to and Facilitators of THtD from CCUs

| **Barriers** | **Country of published work [reference list ID].** | **Facilitators** | **Country of published work [reference list ID].** |
| --- | --- | --- | --- |
| **A lack of empirical research and clinical guidance** | UK [25, 55, 66, 67], USA [59], Australia [60], New Zealand [50], Taiwan China [58] | Evidenced guidelines | UK [66-68], USA [59] |
| **The CCU environment and culture including:** | UK [25, 66, 68], USA [59], Australia [63], Netherlands [53], Tunisia [51], Taiwan China [58] | **Engagement of a Multidisciplinary team (MDT)** | UK [25, 62, 66, 68], New Zealand [48, 49, 72], USA [59], Australia [63] |
| * HCPs’ attitudes | UK [67], Netherlands [57] | Clinicians’ positive views and family members’ agreement | UK [25, 62, 66, 67], USA [54, 59], New Zealand [48, 50, 72], Denmark [64], Netherlands [53], Australia [60], Tunisia [51, 52], Taiwan China [58] |
| * Patients’ high care needs and complex interventions | UK [25, 55, 62, 67], Australia [60, 63], USA [59], Denmark [64], New Zealand [49], Tunisia [52], Taiwan China [58] |  |  |
| **Practical and logistical factors, including:** | UK [56, 62, 66], New Zealand [48, 72], USA [59], Australia [60], Tunisia [52] |
| * Uncertainty and time pressures, staffing levels | UK [25, 55, 62, 67, 68], New Zealand [49, 50, 72], USA [54, 59], Australia [60, 63], Netherlands [57] |
| * Unknown or limited support/resources | UK [25, 55, 62, 66, 68], New Zealand [48, 49], Australia [60], USA [59] |
| **Family members’ expectations and reactions** including:  Family disagreement, unrealistic expectation and inability for home care | UK [25, 55, 62, 68], USA [54, 59], Australia [60], New Zealand [72], mainland China [70, 71] | **Personal patient and family’s wishes informed by cultural norms** including:  Family involvement, engagement and preparation. | UK [25, 55, 56, 62, 66, 68], USA [59], New Zealand [48, 49, 72], Australia [60, 63], Denmark [64], Netherlands [53, 57], Tunisia [51, 52], Taiwan China [58] |

**Barriers to THtD**

**A lack of empirical research and clinical guidance**

A key barrier to embedding transfer practice was linked to the fact that THtD from CCUs was reported as a rare event with little clinical guidance being available [25, 55, 67]. Many units had no experience of transfer [49, 53, 55, 66]. Clinical settings in the UK [25, 31, 66-68] and the USA [59] had established evidence-based guidance from HCPs’ experience gained from transferring patients home. These guidance documents provided general points to consider in implementing THtD practices, e.g.: assessing the patient potential for transfer, what to consider when preparing for transfer, thinking about what may be needed and potential risks during transfer, roles and responsibilities of HCPs and family members on arrival home and after death. However, these guidelines required application and testing in clinical practice to establish its efficacy across contexts of critical care. Where evidence-based guidance was available this facilitated the inclusion of this practice in CCU environments.

**The CCU environment and culture**

This broad barrier included attitudinal, operational and logistical factors. In CCUs, the cure-oriented focus of care was evidenced as a barrier inhibiting clinicians considering THtD [53, 58, 63, 66]. The initiation of decision-making about care transitioning from the CCU to a home environment was difficult for critical care HCPs as they perceived that they facilitated a ‘good’ death in the CCU [63].

*HCPs’ attitudes*

One UK national survey found that a small number of HCPs viewed transfer as “a waste of resources” or “not a priority compared to other care” [67]. The literature clearly indicated a debate around the transfer of unconscious patients who were perceived as being unable to gain any benefit from dying at home [57]. In the West HCPs were reported to consider THtD if it was the patient’s wish [50, 55, 64, 68] as a means of honouring their personal choice or the choice of their family [62, 63, 68, 72]. Of note is that the retrieved literature suggested that the majority of doctors and nurses in critical care held a positive view of the option of transfer for selected patients [25, 48-53, 58, 59, 63, 64, 66, 72] and that THtD was more likely where doctors and nurses had previously had a positive transfer experience [67].

*Patient high care needs and complex interventions*

The timing of a death or life expectancy post transfer, which varied from minutes to months after WLST, were concerns that inhibited consideration of THtD from CCUs [49, 54, 60, 72]. Due to the critical status of patients, as illustrated in patient characteristics (above), decision making was perceived as time consuming leaving little time for implementing transfer [25, 60, 68]. Perceptions of time pressures were compounded by the need to involve a number of individuals in implementing transfer [59, 62]. Transfer was reported as a complex process characterised by unknown or limited support and resources, specifically linked to what was available in community care settings [25, 49, 53, 59, 60, 68].

**Practical and logistical factors**

Considerations regarding the impact of implementing transfers on staffing levels, unit costs, legal requirements and the safety of staff and patients were barriers to THtD from CCUs [25, 49, 50, 57, 60, 63]. Further practical barriers included: the distance between the hospital and patient’s home [48, 52, 59] as HCPs perceived a long journey home would increase the likelihood of death during transit and this concern prohibited consideration of transfer. The retrieved evidence indicated that knowledge of: who in the community would provide: symptom management, support to family members, provision of equipment (e.g. a bed) [49, 55, 62] and death certification at home [48, 55, 66] were essential for transfer to be implemented. Service provision in the community directly impacted transfer decision making as only those patients who the community care team were perceived as being able to care for were considered for transfer [53, 60].

**Family members’ expectations and reactions**

Disagreement among family members or between family and HCPs was an obstacle to THtD from CCUs identified in the USA [54, 59] and China [70, 71]. Disagreements among family members about handling the death at home [59] and signiﬁcant family conﬂict on arrival home [60] were reported. Different goals of care between clinicians and family members [54] were also reported as a barrier to transfer practice.

Families’ unrealistic expectations about death at home after transfer were reported as a barrier to THtD by HCPs in the UK [68]. Several studies indicated that achieving transfer required families to understand what would happen during and after transfer [48, 49, 59] and be able to cope with performing care at home post transfer [25]. In their limited transfer practice, some CCUs in the West excluded patients from THtD if it was deemed that the family could not cope with the process of home death physically or emotionally [25, 49, 55, 59]. Therefore, the literature suggested that consensus among the treatment team (in and out of hospital) [25, 53, 60, 62] and family members [51, 53, 66] was a key facilitator in implementing THtD.

**Facilitators of THtD**

The review identified key facilitators to implementation of the option of THtD and these included: engagement with the multidisciplinary teams (MDT) and personal patient and family members’ wishes.

**Engagement of an MDT**

A facilitator of THtD adopted in the West was the use of an MDT approach connecting divergent care teams’ (primary, secondary and tertiary care) views, needs and expectations [25, 48, 49, 66, 68]. The retrieved evidence indicated that in the West critical care teams mainly worked in partnership with HCPs from palliative/hospice care teams [55, 56, 59, 63, 66], general practitioners (GPs), district nurses from community care services [25, 66, 68], and clinical specialists [56, 60, 62], to plan and implement THtD, whereas, studies of Chinese practices did not report the inclusion of MDT in the decision-making of THtD. Co-operation for transfer between different care teams and planning for transfer had to be established through communication or meeting and clarification of individuals’ roles and responsibilities [49, 59, 66]. In those clinical areas where THtD had been undertaken practice guidance was often based on transfer protocols developed for inter-hospital or between hospital transfers [32, 33, 73], and these were useful tools on which to base development of THtD protocols. In addition to an MDT approach, a ‘nominated person’ was recommended to facilitate and lead the process of transfer as a single point of contact [25, 68, 72].

**Personal patient and family members’ wishes**

Cultural and religious traditions that required a death at home acted as a facilitator for HCPs, wider teams and family members, particularly for populations of Maori and Pacific Island families [48, 49], Muslims [51, 52], and Chinese living in China [58, 65, 69, 70].A death at home after transfer was viewed positively by families and HCPs [53, 55, 62].

Studies indicated that in the West, it was common for THtD to be requested by patients, or by family members who shared the known wishes of the dying patient with HCPs [53, 55, 56, 60, 62-64, 66, 72]. The role of family in the decision-making process around THtD was reported in a number of studies [25, 48, 49, 51, 52, 54, 58, 68, 72] and was outlined as being an informational resource for HCPs clarifying the wishes of the dying or deceased regarding THtD. Papers reporting transfer in China suggested that THtD was often requested by family members [58, 61, 70, 71], where the decision not to WLST could be made by family members even when going against the patient’s own wishes or the doctors’ advice [65].

Transfer was facilitated by a good relationship between HCPs and family members where the family felt involved in the decision-making process. Evidence from New Zealand indicated that HCPs’ decision making about which patients to transfer home was informed by a perception that a close and trusted relationship existed between clinicians and family members [48] and that an ‘open relationship’ with the family had been established. An open relationship was defined as the ability to hold detailed planning conversations with family members in which the family engaged. Planning conversations needed to include preparation of the family for all potential eventualities resulting from a decision to THtD, including death in transit [49].

A key finding from the review was that in CCUs THtD was not a routine consideration in EoL care planning with this option only being considered if the patient or family request it [25, 66] and that key facilitators needed to be in place for this option to be operationalised.

Discussion

This review has identified factors and processes that act as barriers and facilitators to THtD from CCUs, mainly derived from research undertaken in the West. The review has illustrated a paucity of clinical and policy guidance for THtD from CCUs globally. While there are guidelines for EoL decision-making in critical care [40, 74-76] and for inter-hospital or between hospital transfers transfer [32, 33, 73], the lack of guidance around THtD is an important gap in the evidence base.

A key issue in decision making around THtD is evidenced as the high care needs or complex interventions required by the patient in CCUs which were perceived as barriers to considering the option of THtD in the West. Adverse events or unexpected events are reported to be as high as 25% in intra-hospital and inter-hospital transfer of critically ill patients [77-79], with serious adverse events leading to termination of the transfer [77]. Complexity is salient in all types of transfers [32, 80] and therefore THtD is not an option for all patients in CCUs in the West even if their preference is for a home death.

Findings indicate that positive views and consensus among HCPs, the expressed wishes of patients and family members toward THtD influence implementation of this option. In the West, the personal wishes, or preferences of dying patients or family members dominate decision-making and planning, but these preferences may only be considered when implementation of THtD is perceived to be in the best interests of patients and family members. In Eastern cultures such as China, transfer is a cultural requirement considered mandatory. In China, families are commonly involved in patients’ care decision-making even when patients have capacity to make decisions [81, 82]. However, they are not included in the transfer decision-making process by ICU doctors [83]. For Chinese people, home has a special cultural meaning [21] and dying at home is seen as a way of continuing bonds with one’s ancestors [84]. Global literature reports that home has special cultural, religious, and spiritual meaning as a place of death for many ethnic groups [83, 85, 86] and therefore it is essential that HCPs seek to meet cultural expectations around death and dying even in the face of complexity.

However, instigating change in practice is challenging as evidenced by the implementation research literature which has demonstrated that HCPs’ views regarding innovation or change in practice are factors enabling or inhibiting successful implementation of that change [87, 88]. While this review has identified that HCPs are positive about the option of THtD, for many this is an innovative practice requiring changes to practice therefore other facilitative factors are needed to sustain practice change.

Studies from across interdisciplinary working [89] report the facilitative impact of MDT working and this is reflected in this review. The inclusion of palliative and community care teams in the planning and the implementation of: early communication, shared decision-making, and goal setting underpinned compassionate collaborative care at end of life [90, 91] which included the option of THtD. A key issue of note is that in some cultures and health care systems, MDT working and the inclusion of family members in decision-making is not part of routine practice, nor is there a culture of EoL planning [83].

The extent of family involvement in transfer decision-making varied from a supportive role in the West to an active dominant role in mainland China. For a patient to die at home requires not only advanced planning but is heavily dependent on a perception that family caregivers are available, willing, healthy, and capable to support patients who are transferred home to die [92].

As indicated in this review THtD is a rare event and so family members would have no basis upon which to consider what could or would happen. While dying at home for those patients from outside CCU environments is not unusual [7, 93, 94] the impact of a patient dying at home on family members is an issue reported in palliative care research [95]. Survey data reported that almost half (48%) of 1628 caregivers of patients at EoL stage reported a worse or much worse than expected caregiving experience due to a lack of: appropriately delivered and accurate information, misinformation gleaned from a variety of sources, and a lack of experience or exposure to death and dying [96]. In view of the complex care often required by CCU patients at EoL stage preparation of family caregivers is an essential aspect of planning that is currently limited in clinical practice [32, 33].

Conclusion

To the best of our knowledge, this is the first systematic scoping review summarising the international literature on the practice of THtD from CCUs. Findings from the review report that THtD is an international phenomenon but varies in the way it is operationalised in different healthcare systems and social contexts. In Western countries, THtD from CCUs is a rare, complex practice and is motivated by personal patient and family preferences while in eastern countries particularly China THtD is a cultural and traditional expectation. Patient characteristics influence decisions about who will and who will not be transferred home in Western health care systems, but less so in none-western systems and whereas family members play a key role in achieving a transfer in Western health care systems they have no role in decision-making in none-western systems.

Recommendations for future research

The review has shown that current understanding about THtD from CCUs is based on a limited evidence base of non-empirical evidence and retrospective observations reported in clinical case reports. Empirical research, including in-depth exploration of the decision-making process underpinning THtD across clinical contexts globally is needed as is a detailed investigation of the trajectory of dying that takes place in the home environment following THtD. Undertaking this research could lead to practice change that prioritises the EoL wishes of patients and family members to ensure that dying at home is a viable option for those patients whose critical care treatment needs to be withdrawn and for those family members who will care for the dying patient in the home.

Strengths and limitations of the review

A systematic scope of the available literature was conducted applying the PRISMA-ScR and the JBI frameworks. While, only YL undertook initial title and abstract screening, all papers for inclusion in the final data extraction were reviewed by MM and TLS and consensus achieved.

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# Ethical Approval

None.

# Conflict of interest

There is no conflict of interest declared.

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