End of life care (EoLC) in adult intensive care, family involvement and bereavement services worldwide:

A narrative review

Dr Zoe Brummell
Churchill Fellow 2023

Executive summary

Project aim

The ultimate aim of this project is to improve family involvement in end of life care (EoLC) in adult intensive care in the UK. This project will seek out and provide best practice evidence for EoLC in intensive care with regards to involving family and loved ones in EoLC. This project will build on the work undertaken by the Faculty of Intensive Care Medicine looking at care at the end of life. [1] This review will seek to understand the best ways to communicate with and to provide family centred care. In doing this I hope the mental health and wellbeing of families and those important to patients will be maintained and that the risk of developing complex grief will be reduced. I also hope that multidisciplinary teams in intensive care units will feel better able to support families in EoLC.

Project objectives

- Develop an increased understanding of the methods and interventions used to involve families in EoLC in adult intensive care units
- To understand the provision of bereavement services available to families of patients in intensive care
- To speak to staff (and patient families) in the intensive care units to understand how these methods work in practice
- To develop relationships with clinicians/researchers for future research and improvement collaborations
- To utilise my findings to develop best practice guidance to improve family involvement and bereavement services for EoLC in the Intensive Care Unit (ICU) at University College London Hospitals (UCLH)
- To utilise my findings to improve family involvement and bereavement services for end EoLC in the intensive care unit on a national level

Personal interest in EoLC in adult intensive care

The development of my interest in EoLC within the adult ICU has been multifactorial. My PhD evaluated the 'Learning from Deaths' UK healthcare policy (2017). During this I met many bereaved families with complex grief who had been poorly treated and communicated with by individuals and organisations. As a consequence of this I undertook training to become a Medical Examiner where contacting and communicating with bereaved relatives occurs frequently. Over the course of my career, I had often wondered what became of the families I had met and formed connections with whose relatives died, especially once I had started Intensive Care Training in 2012. Then during the Covid-19 pandemic, contacting relatives by phone to inform them that their loved one had died increased this curiosity, so I volunteered for Cruse Bereavement Support (a national bereavement charity) and undertook their excellent bereavement training to become a bereavement support volunteer. [2] I am currently a Consultant in Intensive Care and Perioperative Medicine at University College London Hospitals (UCLH), where looking after patients at the EoL and communicating with

their families is commonplace. Since applying for this Fellowship, I have joined the pan-London EoLC in Intensive Care group.

Countries involved in this Fellowship

The choice to involve and visit specific individuals, groups and countries was multifaceted. Prior to applying for the Fellowship, I already had awareness of international ICU research groups who had significantly published in this field, particularly Prof Randall Curtis and team in Seattle, USA, who had made improving patient clinician communication particularly at the end of life, his life's work. It was also evident that Prof Rebecca Aslakson in Vermont, USA had undertaken a significant amount of research in this area, as had Prof Elie Azoulay in Paris, France. Unfortunately, Prof Curtis died in February 2023 [3] and then a United Kingdom (UK) expert in EoLC in adult ICU (Dr Victoria Metaxa from Kings College Hospital, London) recommended against visiting the USA since the funding structure and culture are not comparable to that of the UK. In view of this and after further background research I chose to visit in person Prof Elie Azoulay's group in Paris, France and Prof Brandi Vanderspank-Wright and team (including Prof James Downar) in Ottowa, Canada. Both of these groups have published extensively in family involvement in EoLC in adult intensive care. In addition, I arranged to meet remotely (via videoconference and email) groups and/or individuals from Wellington and Hutt (New Zealand), Vermont (USA) and Leeuwarden (the Netherlands).

EoLC in adult intensive care at UCLH

University College London Hospitals has 4 separate ICUs/HDUs, our main general unit (up to 25 patients) can take paediatric patients down to the age of 12 years. One of our units (9 beds) is dedicated to haem-oncology patients, the other two are surgical: one elective (10 beds) and one a mix of electives and emergencies (9 beds). Our mortality is very unit dependent, 1.1% in the elective surgical setting and up to 18.7% in the haem-oncology unit (2023). Because of our case mix we don't do as much organ donation as other big hospitals in London (we don't have any trauma) but have over 3000 admissions a year. At UCLH EoLC in ICU is provided with a multi-disciplinary approach, we have significant support from a clinical psychology team and have very close links with the palliative care team in our EoLC approach.

Acknowledgements

I'm extremely grateful to the Churchill Fellowship for enabling me to undertake this fellowship. I'd also like to express gratitude to all the professionals who gave me their time and expertise freely, I'll be forever grateful. I'm particularly grateful to Prof Brandi Vanderspank-Wright for organising the programme of activity for me in Ottawa and to Prof Elie Azoluay for fitting me into his busy schedule.

“It seems to me, that if we love, we grieve. That’s the deal. That’s the pact. Grief and love are forever intertwined. Grief is the terrible reminder of the depths of our love and, like love, grief is non-negotiable”

Nick Cave, Red Hand Files, 2018

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Introduction

The possibility of intensive care units (ICUs) came into existence with the invention of the first ventilator in 1929. [4] Not long after this time a Harvard Medical School physician (Dr James Wilson) treating children with Poliomyelitis recognised the ethical difficulties that came with these advances, stating that '*we would be forced to use the respirator indefinitely or until someone should turn executioner by stopping the machine'*. [5] For the following few decades the focus of ICUs was on prolonging life. The realisation that ICUs might be prolonging death became more public in the 1970s, when a Danish anaesthetist (Dr Bjorn Ibsen) who was intrinsically involved in managing the Copenhagen Polio epidemic stated this concern in a radio broadcast. [6] Palliative care first came into existence because of the hospice movement in the 1960s and was recognised as a specialty in the United Kingdom (UK), Australia and New Zealand in 1987. [7] The increased involvement of palliative care and/or the recognition of the need for better end of life care (EoLC) in ICU grew exponentially during the early 2000's. [8]

Hospital is currently the most common place of death in England, although this varies widely across the country with the range being from 37.2% to 50.8% in 2022. [9] The most recent UK National Survey of Bereaved People (2015) found that there were higher rates of poor communication and poor understanding of information for bereaved families in hospitals than in other settings. [10] Poor communication is the biggest cause for written complaints within the NHS. [11]

Being aware of patient priorities for EoLC (place of care and death) is considered part of good quality healthcare. [12] Healthcare professionals in both primary and secondary care should be supported to have these conversations with their patients and encourage patients to ensure their families are aware of their priorities. An increased awareness would help to lessen the burden on families to second guess what their loved ones might have wanted. The reasons EoLC is not as well managed as it could be in these settings may include that healthcare professionals see death as a failure in their duty to make people better. [13] This perception may result in inappropriate treatments which do not significantly alter the outcome for patients and perhaps offer false hope and confusion for families. In addition to this, prognostic uncertainty is commonly cited as the reasoning behind healthcare professionals avoiding EoLC conversations. [14, 15, 16]

EoLC in adult Intensive Care in the UK and around the world

Worldwide approximately 10 to 29% of the patients in adult ICUs die, with a 35% relative decrease between 1988 and 2012. [17] In high-income countries mortality rates in ICUs are overall lower (8 to 18% in 2010) than in low-income countries (46% in Tanzania in 2019). [18, 19, 20] In the UK in 2022-23 across 267 ICUs, risk adjusted acute hospital mortality was 17.7%. [21]

Critical care varies significantly around the world, not only due to inherent cultural differences and health expectations between countries, but also due to differences in healthcare funding, healthcare organisation, patient case mix and population health status. [22]

The ETHICUS study (2019) found significant variation in EoLC practices across Europe with regards to undertaking CPR and Withdrawing Life Sustaining Measures (WLSMs). [23] A later study, ETHICUS 2 (2020) demonstrated that practice across Europe (and North America/Australia/New Zealand) was becoming more homogenous with less CPR and more WLSMs. [24]

In the UK in 1985 a letter published in Anaesthesia by a theologist commented that '*ethical questions arise in Intensive Care because the practice is dominated by a tension between 'a right to live' and a 'right to die'*. [25] In the UK Faculty of Intensive Care Medicine (FICM) 2019 report: 'Care at the End of Life: A guide to best practice, discussion and decision-making in and around critical care', [1] recommendations are made with regards to family involvement and to a lesser extent bereavement support:

- Families should be invited to participate in end-of-life care provision to enhance awareness of dying and develop family-centred care
- Bereavement care is highlighted as invaluable for helping families (but there is no detail in the report around what this should or shouldn't include)

The 2019 FICM report focused on advanced care planning, EoL decisions, and EoLC. It emphasised family involvement in EoLC to help prepare for bereavement and the role of the healthcare team in supporting families with consideration for both individual and cultural needs. [1] The American Academy of Critical Care Medicine has gone further and made recommendations that bereavement support should be a clinical and research priority. [25] The World Federation of the Societies of Intensive and Critical Care Medicine reported on EoLC in the ICU across the world (2016). The report summarised statements from intensive care organisations and noted the wide variation in EoLC practices, research initiatives, education and training initiatives across the globe. [26]

Earlier (1998) UK guidelines from the Intensive Care Society (ICS) outlined the importance of bereavement services in ICUs, following a nationwide survey. The guidelines recommend training in bereavement care and communication skills, identifying a named lead for bereavement care, as well as providing information around local services and groups able to help bereaved families. The importance attached to bereavement services by the ICS 1998 guidelines has not been mirrored in the more recent 2022 ICS/FICM Guidelines for the Provision of Intensive Care Services (GPICs) – which makes no mention of bereavement care. [27]

Despite the UK published guidance in EoLC in adult ICUs and clear interest in EoLC sessions at ICU Conferences, there is little UK published research around EoLC in adult ICUs. The notable exceptions to this are from Dr Victoria Metaxa (Kings College Hospital, London), Natalie Pattison (East and North Herts NHS Trust, Hertfordshire) and Prof Nazir Lone (Edinburgh University). Metaxa (with other collaborators) undertook a national (English) audit on bereavement care in ICUs (2017), found bereavement care to be underdeveloped in English ICUs with less than half of all units having a written bereavement policy. [28] Pattison and Lone reviewed bereavement in critical care (2021), finding little evidence about supporting families bereaved in ICUs. They reviewed the typical bereavement pathway in ICUs and called for further research in this field. [29] Metaxa (and other collaborators) (2021) undertook a review looking at the number and types of palliative care interventions implemented within the ICU setting globally, to assess their impact on ICU practice and to evaluate differences in palliative care approaches across different countries. The different types of interventions were communication interventions, ethics consultations, educational

interventions, palliative care team involvement and advanced care planning. [30] A further Metaxa (and colleagues) review (2023) looked at commonly posed questions arising around EoLC in ICUs. They found that the most common issues included advocacy for the inclusion of families in EoL decision making. [31]

Legal position on patient autonomy and family involvement in healthcare decision making

In the UK doctors have a legal duty to protect life and to uphold the Human Rights Act (1998). Doctors are not legally required to provide a treatment requested by a patient that '*will not achieve any clinical benefit'*. The reasoning behind the decision not to provide a potential treatment should be clearly explained to the patient and a second opinion and/or mediation offered. Where disagreement persists, legal advice should be sought. [32] Where a patient is incapacitated healthcare teams need to consider what treatments would benefit a patient and whether giving these treatments would be in their best interests. Best interest decisions can be made by a legally pre-appointed patient representative with Lasting Power of Attorney (LPA) for health and welfare. [33] Next of kin (without LPA) have no legal weight in decision making but can be asked to help inform healthcare teams of what the patient would have wanted. Ethical decision making around EoLC involving families can be difficult with case law criticising both incorporating and denying families views and involvement. [34, 35] The UK legal position is slightly at odds with the NHS recommendation for shared decision-making. [36] The legal position for EoL decision making, doctor-patient relationships and the involvement of families in EoLC decisions varies significantly across the world. [37]

Death and bereavement

The Lancet commission on the 'Value of Death', 2022 report, discusses the inequity in access to healthcare to extend life and the disproportionate medicalisation of death and dying worldwide, to the extent that the public don't recognise dying as they used to. The report discusses how families have been disenfranchised in supporting their loved ones through the dying process and that the public at large have bought the false narrative that we can control nature (and perhaps avoid death). [38] The commission made five recommendations that:

1. The social determinants of death, dying and grieving are tackled
2. Dying is understood to be a relational and spiritual process rather than simply a physiological event
3. Networks of care lead support for people dying, caring and grieving
4. Conversations and stories about everyday death, dying and grief become common
5. Death is recognised as having value

Grief and bereavement are terms that have been used interchangeably in popular culture. Bereavement is the term applied to individuals who have experienced losses due to death. Grief refers to the reaction to the loss, whether it be emotional, behavioural, cognitive, spiritual or social. [39] For a large majority of people, a typical course of grief lasts up to 6 months and requires no

treatment. [40] Unfortunately, for approximately 10 to 12 % of people grief does not resolve naturally and instead persists indefinitely, contributing to a reduced ability to function often with associated complex emotional, mental, and physical symptoms, this is known as complicated grief. Complicated Grief (CG) is more likely if the death was sudden, traumatic and unexpected. [41]

Bereaved individuals are at an increased risk of both mental and physical health problems. There is no evidence that routine psychological support for bereavement is effective. [42] Predicting the adaption of individuals to bereavement and therefore the susceptibility to complex grief can be done through identifying situational, personal or relational risk factors (these may or may not be modifiable) and/or protective factors. Bereavement theories and frameworks incorporate many of these factors to identify bereavement risk: Integrative theory of bereavement, [43] Attachment theory [44] and Integrative risk factor framework. [45]

The Integrative Risk Factor Framework provides an in-depth analysis of how individuals cope with bereavement. The Integrative Risk Factor Framework incorporates elements of the cognitive stress model, which posits that through a process of cognitive appraisal, individuals experience a given situation as stressful when their coping resources exceed the demands for the situation, and when the situation is personally meaningful. The Integrative Risk Factor Framework identifies bereavement related risk factors, which include the traumatic or 'sudden, unprepared, and untimely' loss of a close loved one. These bereavement related risk factors interact with other risk factors including access to social support and intervention programmes, gender, predisposing vulnerabilities, and appraisal and coping mechanisms to determine the bereavement outcome. [45, 46]

UK bereavement services are multiagency: acute care (hospital palliative care: NHS and private), hospital chaplaincy/spiritual services, primary care (GP, hospices) and third sector (charities, hospices, voluntary groups). The National Bereavement Alliance (2017) recommended that bereavement support for families should incorporate: information about grief and what to expect, formal support for grieving and bereaved individuals and families (volunteers), the availability of specialist support (psychologists, mental health services, counselling, palliative care/bereavement services). [47]

The James Lind Alliance (a clinical research priority setting charity), has highlighted bereavement as a priority both in palliative care and critical care, and across care settings. [48] Bereavement research is also a National Institute for Health Research priority. [49]

In 2024, the Lancet published 'Investing in bereavement care as a public health priority' describing poor resourcing and inequities in bereavement support for families. They recommend a crossover in support between the institution where the family member died and community-based support. They discuss how the second loss of the healthcare team and institution in addition to the loss of their loved one impacts families. They conclude that bereavement should be seen as an inherent element of the duty of care. [50] Bereavement not only causes individual and family mental and physical health problems, but it also has a significant economic impact which should be addressed for the benefit of society as a whole. [51]

Involving families in EoLC and bereavement in adult ICUs

There is international evidence that families of patients who die in ICU sometimes have a traumatic experience of ICU with significant psychological impact and subsequent bereavement. [52, 53, 54] These family members are more likely to experience mental health issues, post-traumatic stress disorder, complicated, prolonged grief and social distress. [55, 56, 57, 58, 59] Studies have demonstrated that bereaved families would like bereavement support, [60, 61] but, as discussed earlier what form this should take is not completely clear. [29, 62] It is difficult for primary care services to provide support and/or advice to bereaved relatives when they often have little understanding of intensive care and have limited resources. [29] In addition healthcare professionals, even in primary care (where the interaction with bereaved individuals occurs more frequently) do not fully understand the risk factors associated with complicated, prolonged or complex grief. [63]

Bereavement interventions (tools) used by critical care units in the UK include family meetings, memorial services, mementoes (locks of hair, handprints) and critical care diaries. The effect of providing these interventions is unknown (beneficial or otherwise). [30] Some reasoning as to why evidence is lacking, is the difficulty researchers perceive in approaching bereaved families. This difficulty is present despite evidence suggesting that some families find involvement in bereavement research beneficial for their own bereavement. [64, 65, 66, 67] There is also evidence contradicting this with Downar et al (2014) finding that 1/3 of family members found it 'stressful' being contacted by hospital staff. However, in this study it was also noted that despite this increased stress family members would prefer to be contacted than not and overall, the study concluded that bereavement screening and support for family members was needed. [60]

A 2019 review (Efstathiou et al, 2019) looked at bereavement support in adult ICUs internationally. This review found five studies that report the state of bereavement support in ICU across the world (Australia, New Zealand, Denmark, UK, USA). They found the most common support services offered are a condolence letter/card, a phone call, a meeting, a brochure on bereavement services (either hospital or community). They found a lack of training, a lack of educational support and resource (financial and time) challenges as barriers to providing bereavement care. [68] Efstathiou et al found nine studies that reported on ICU bereavement support interventions (Canada, France, Sweden, USA). These interventions were single and multicomponent. Single component interventions were journalling, rhythm strip memento, a storytelling intervention, [69] routine follow-up meeting, participating in bereavement research and a condolence letter [70]. Only one study provided multicomponent interventions: formal follow-up, bereavement brochure, sympathy/condolence card (10 days post death), telephone follow-up and invitation to hospital memorial service. The multicomponent study authors recommend including bereaved family members at the inception of follow-up programme design. [71] Efstathiou et al noted methodological shortcomings in the evidence from the review, finding that the adequately powered studies demonstrated no effect in a range of interventions, and that one study even suggested worse psychological morbidity in families randomised to receive a personalised condolence letter compared with usual care. [68]

A similar systematic and narrative synthesis review was published in 2021 (Moss et al), this utilised robust outcome measures as described by Harrop et al (2020), for bereavement research to assess

impact of bereavement interventions on families. [72, 73] They identified three studies (1 in France and 2 in the USA). These interventions were:

- a storytelling intervention [69]
- a condolence letter [70]
- presence during brainstem testing [74]

This review identified family presence during brain death evaluation and storytelling as feasible and acceptable interventions among family members, although neither intervention was found to improve the emotional and psychological wellbeing of these individuals at 3 to 6 month follow up. In this review no bereavement intervention was found to significantly alleviate grief symptoms or improve the ability to cope. [72]

It is important to recognise that it is difficult to support ICU relatives without acknowledging and supporting the ICU staff experience of death and dying. This support should include training in communication and in providing bereavement support to patients and their families. [75, 76, 77] This support and training isn't routinely provided for ICU staff in England. [78] A 2019 Canadian study (Kalocsai et al, 2020) looked at how critical care clinicians (nurses and physicians) perceived grief in family members and their bereavement support offer. More than 80% reported supporting families before or at the time of death, however, less than 6% followed up with bereaved families in the days or weeks after death, as this was not part of their standard approach. Any after death support was usually family initiated. Most staff felt that bereavement starts before the patient dies and recognised the impact that interactions with staff could have on grief. Clinicians also recognised a difference in their understanding and perception of the dying process from that of family members (or the wider public). In this study, most clinicians (82%) would like to receive formal bereavement support training and approximately half wanted to provide emotional support to families if given the time and training. [79]

Findings from meetings

Canada: The Ottawa Hospital

https://www.ottawahospital.on.ca/en/

Figure 1. Downtown Ottawa

Context to EoLC in adult ICU in Canada

In Canada in 2000 it was approximated that between 52% and 87% of people will die in hospital. The reasons for this are thought to be due to systemic factors and not necessarily due to patient choice. At this time (in 2000), between 7% and 25% of Canadians died in specialist care units such as in ICUs. [80]. In 2005, an article in the Journal of Critical Care discussed the provision of 'futile' care in Canadian ICUs, finding 95% of physicians reporting providing futile care in the ICU in the proceeding year. Reasons given for this were: prognostic uncertainty, family request and legal pressures. The paper describes the perception of healthcare staff that '*death was perceived as treatment failure'* and the difficulties experienced by healthcare staff in communicating EOL to patients and/or family members. [81]

In 2013 there was a landmark case 'Cuthbertson vs Rasouli' in the Supreme Court of Canada, ruling that the withdrawal of life support (WLS) in certain circumstances is a treatment requiring patient or substitute decision maker consent. A 2015 study surveying Canadian intensivists on the impact this ruling had made to their practice found an increase in the intensity of inappropriate treatments provided to patients and significant variation in how intensivists approach EoL disputes. [82] Since this time a Canadian study (2016) has found that when palliative care teams are involved in ICU care symptom control is improved, length of stay is shorter and resource consumption is reduced. [83]

In June 2016 Canadian law changed to allow medical assistance in dying (MAiD), both assisted suicide and euthanasia. The majority (but not all) healthcare staff support the availability of MAiD. [84] In 2022 MAiD accounted for 4.1% of all deaths in Canada, with an increase of more than 20% each year since its introduction. [85]. The majority of recipients of MAiD are white (96%) and have completed higher education (75%). [86]

In 2022 Andersen et al reviewed the effect MAiD has had on EoLC in ICU; they found a wide range of opinions on MAiD (due to moral, ethical and/or religious beliefs), but the majority of Intensivists did not think it had substantially changed ICU practice. The main reasoning for this was because the majority of ICU patients do not have capacity and this is an essential requirement in consenting for MAiD. [87]

In 2024 Shapiro et al reviewed senior medical opinions with regards to MAiD and how it had impacted palliative care services across Canada; there were differing opinions about whether MAiD and palliative care services should be integrated, separate or coordinated and what can be done to improve the relationship between these services; through public education, compassionate and proactive leadership, standardisation of practice guidance, fostering cultural and religious understanding. [88]

An evaluation of the perceived need for (and barriers to) integration of ICU and palliative care and quality of EoLC at four hospitals in Ottawa was studied in 2020. Both ICU and palliative care healthcare professionals participated. The study demonstrated that most respondents (78.4%) thought increasing ICU and palliative care integration was beneficial (100% of palliative care physicians thought integration was beneficial). The best strategies for doing this were 'criteria-triggered consults' to palliative care and role-modelling/training of ICU trainees in EoLC. The main barriers to integration were a lack of understanding of the role of palliative care, inadequate communication about the negative impacts of ICU care and (over)confidence by intensivists in their own ability to deliver good palliative care. [89]

The Canadian Constitution Act formally recognises three distinct groups of Indigenous Peoples: First Nations, Métis, and Inuit. [90] It is recognised both globally and in Canada that health inequities exist for indigenous people, resulting in worse health outcomes for these populations. [91, 92] A systematic review and meta-analysis in 2023 found no difference in mortality following ICU admission for Indigenous people but did find a difference in the ICU length of stay (shorter in indigenous population) and use of mechanical ventilation (less in indigenous population). [93] The Pan-Canadian Palliative Care Research Collaborative and Cancer Care Ontario provide a multitude of resources for improving EoLC, including palliative care and bereavement toolkits for Indigenous communities. [94, 95, 96]

Thoughts and questions prior to meeting

My main reasoning for this visit was to see EoLC in adult ICU in a health system with some similarities to the UK, to understand the EoLC experiences of clinicians and family members within the ICU. To understand the methods and interventions used to involve families in EoLC and to look at the provision of bereavement services available to ICU families. I was aware that Prof Brandi

Vanderspank-Wright (an ICU nurse by background) and Prof James Downar (a dual trained ICU and palliative care Consultant) based in Ottawa were widely published in this area and wanted to see the clinical impact of this research in their hospital. I also wanted to better understand the impact of MAiD on the public narrative around death and dying and any impact this had, had on WLS in the ICU.

Individuals and in person group discussions: The Ottawa Hospital

The Ottawa Hospital organisation consists of three geographical separate hospital campuses: Civic campus, General campus and Riverside campus. I visited the ICU on the General campus, which is similar to UCLH, with general medical, surgical and haematology/oncology patients. They also have the same electronic health record system as UCLH. They have open visiting for families when patients are EoL. Visiting in general is open except for during staff handover.

Over several days I met multiple colleagues including: Prof Brandi Vanderspank-Wright (Professor in Intensive Care Medicine), Danny Sutton-Long (Specialist Nurse in Organ Donation), Alicia Robblee (ICU Nurse Educator), Prof David Wright (Professor in Palliative Care) and Prof James Downar (ICU and Palliative Care Consultant). Within the ICU I saw ICU patients with families and staff working (doctors rounding, dietician reviewing notes, nurses caring for patients). I did not have the opportunity to speak to any families during this visit as there was no-one suitable.

Figure 2. The Ottawa Hospital outside the ICU

Some of the topics covered during my visit included:

- **Methods and interventions used to involve families in EoLC**
    - The Withdrawal of Life Support Measures order set
    - Initiatives to improve EoLC for families and for staff (butterfly initiative, post-code pause and 3 wishes project)
    - Cultural and religious education
    - How organ donation has improved EoLC in ICU
- **The provision of bereavement services available to families**
    - Bereavement support for families of ICU patients
- **How these methods work in practice**
    - Initiatives involving all stakeholders
    - The importance for staff of 'being able to make a difference'
    - The public difficulty in accepting that 'death is part of life'
    - Building relationships, making time and space for families
    - Dual ICU and palliative care training and jobs
    - Impact of MAiD on EoLC in ICU
- **EoLC in ICU research**
    - Difficulties in doing research, evidencing benefits and implementing findings

Methods and interventions used to involve families in EoLC

The Butterfly initiative consists of the placement of a butterfly sign on the door outside the EoL patient room. This sign lets others know that this patient is at the EoL so staff can behave accordingly when entering the room and interacting with the patient's family. This symbol is also used in other intensive care units in Canada. This is similar to the swan symbol that we use at UCLH.

The post-code pause (PCP) occurs immediately after a death following unsuccessful resuscitation. A member of the resuscitation team reads out a short text: '*Let us take a moment to pause and honour (name). He/she was someone who loved and was loved – was someone's family member and friend. In our own way and in silence, let us take a moment to honour (name). Let us also honour and recognise the care provided by our team*.' This creates the opportunity for clinicians to honour the patient and the significance of what has occurred prior to moving onto the next task. The PCP was pioneered by Emergency Department nurses from Colorado in 2016, where the pause begins with 10 to 15 seconds of silence and is followed by 7 debriefing questions. [97]

The 3 wishes project is an EoL intervention in which clinicians implement small, but meaningful, final wishes for dying patients and their families in the hospital. There are three objectives of this initiative:

- For patients, to dignify their death and celebrate their life
- For family members, to humanise the dying process and create positive memories
- For ICU clinicians, to foster patient and family-centred EoLC and inspire a deeper sense of vocation

In Ottawa General to help with this project they have a cart with items to make the ICU room more comfortable for families and provide mementos for families (fingerprints, rhythm strips). The 3 wishes project was initially developed in Hamilton, Ontario in 2013 and is spreading out across

Canada and the United States of America in over 20 ICUs. [98] Qualitative research has demonstrated that this project is viewed positively and valued by hospital leaders and recognised that '*the non-medical aspects of care often determine the patient and family hospital experience'*. [99] The 3 wishes project has been taken up by East Kent Hospitals in the UK. [100]

The Withdrawal of Life-Sustaining Measures (WLSM) order set consists of several assessments and interventions that are requested by the clinicians on the Electronic Health Record platform (EPIC) to be undertaken by the nursing staff looking after the patient. This includes many components such as discontinuing treatments and patient/family assessments (see figure 3).

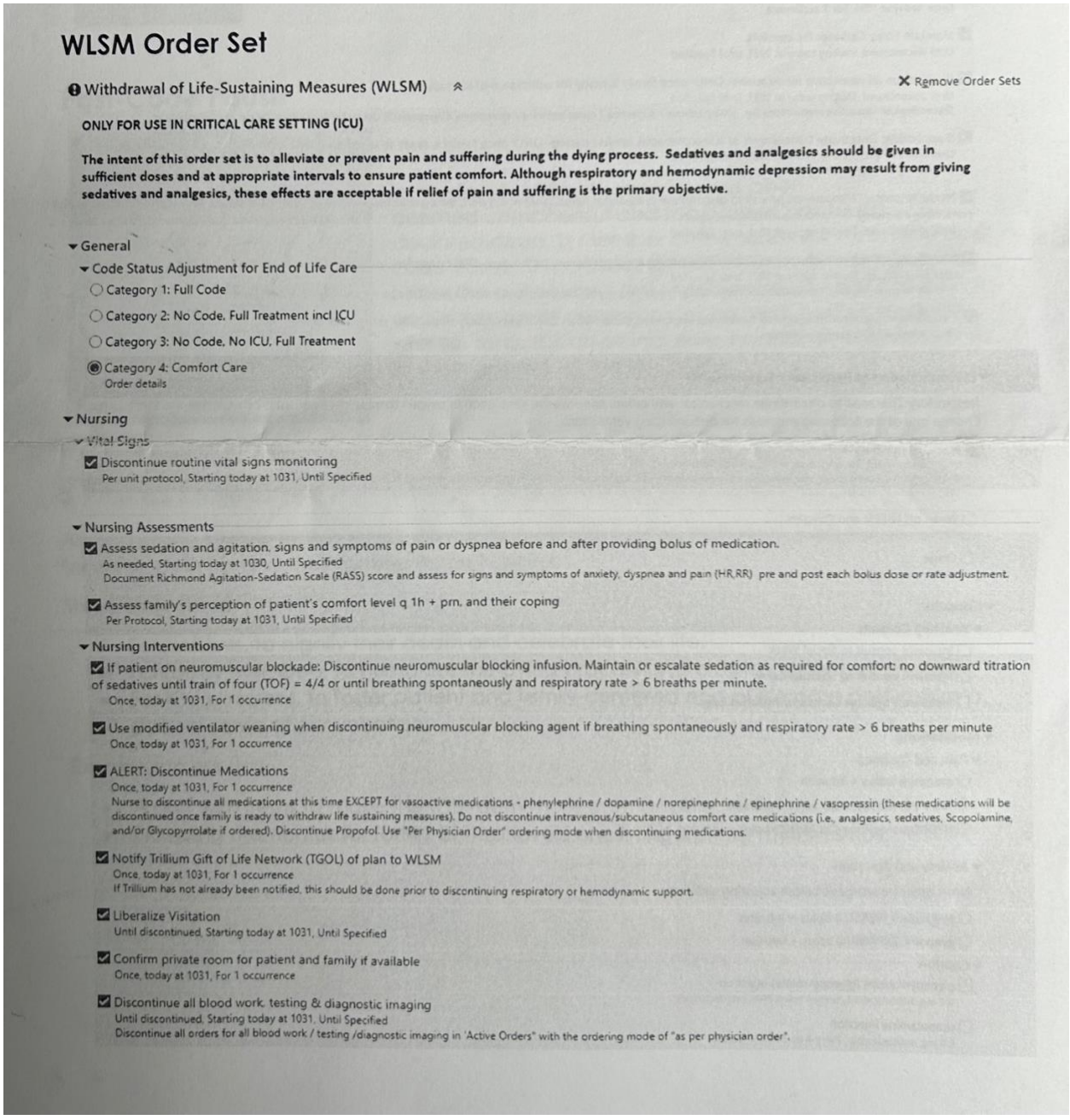

Figure 3. The Ottawa Hospital Withdrawal of Life Sustaining Measures order set

The Ottawa Hospitals group currently has a lunchtime programme at the Civic Hospital where members of different religious communities come to speak to hospital staff about their beliefs, rituals and practices around death and dying.

The organ donation programme in Canada is unlike that in the UK, it is not under the care of one unified organisation and is instead run by multiple separate organisations. The programme at Ottawa Hospitals has enabled improved family support through organ donation and after donation during their bereavement, with a follow up call immediately (1-2 days) post death and then at 3months, 6 months and 12 months. The organ donation team have found that their involvement improves family support in EoLC and appears to reduce complex grief. In studies the impact of organ donation on bereavement has been found to be mixed, with evidence of no effect, negative and positive impact of organ donation on relatives, with positive impact where communication was of good quality and relatives felt listened to and a negative impact where relatives felt they had unanswered questions. [101, 102]

Figure 4. Outside the Ottawa Hospital ICU, organ donation celebration

The provision of bereavement services available to families

Prof Vanderspank-Wright had been planning a research study looking at several different bereavement support measures utilised in tandem, unfortunately this was abandoned due to the Covid-19 pandemic. This study included bereavement training modules for the multidisciplinary team (this training can be found at www.icugrief.ca), a condolence letter, a phone call to ask if willing to take part in research, and an optional meeting with hospital staff to undertake a narrative review ('story-telling') intervention. [69] Prof Downar agreed that a narrative review intervention (a single facilitated session in which family members can explain their bereavement experience) had evidence behind its effectiveness.

There were several discussions around the reasoning and evidence in choosing bereavement interventions both for research and for quality improvement. Some interventions appear to be

standard practice in certain ICUs and not additional interventions such as in the White et al (2018) study where the major intervention was daily family updates. [103] We discussed the difference in what would be considered appropriate in different settings, for example I'm not sure the use of an ECG trace as a memento (used in California, USA) would be appropriate in the UK. [104] We discussed journalling (by ICU staff) as a way to ensure family had something to look back on from their time in ICU – it was agreed that this might be useful. Journalling was used by several ICUs in the UK during the Covid-19 pandemic and has been used by other ICUs outside of the pandemic. [105, 106]

How these methods work in practice

The nursing staff I met, and the research work produced by these individuals holds a strong message that '*being able to make a difference*' is important for staff. One of Prof Vanderspank-Wright's PhD students Heather Stokes commented in her thesis that '*the participants created a space that was more aesthetically pleasing and home-like for the family by manipulating the ICU environment to make a space where the family could mourn, grieve, and have cherished private moments with their loved one*.' [107] One of Prof Wright's PhD students Kristina Ma Thesis looked at the moral experiences of ethically meaningful situations in EoLC and in part discusses that people are unable to accept that '*death is part of life*'. [108] This belief is further compounded when patients are in ICU because relatives (and ICU staff) expect patients to come to ICU to survive and not to die. [109, 110]

We discussed at length whether the nurse experience reflected patient/family experience and concluded that although not entirely clear there does seem to be a correlation suggesting that improving the nurse experience could improve the family experience during EoLC. Prof Vanderspank-Wright suggested improving the nurse experience by providing structure to family meetings (premeeting/meeting/debrief), by planning for outcomes with the family (withdrawing at the right time in the right way), the need for nurse to be 1:1 with patient (to support the emotional burden and to give time to family), the need to give time for the bedside nurse once the patient has died (postcode pause, not to be the next admitting nurse) and to talk more about death and dying. We discussed the importance of working as a team with the nurse, doctors, other multidisciplinary team members, the patient and their family. We discussed the importance of building relationships with families during EoLC: making time and creating space for families. We discussed what making time looked like: liberal visiting, fitting the timing of withdrawal around the family (giving the illusion of time) and that once the decision has been made to withdraw that we should slow everything down to ensure that the family fully understand what is happening. We discussed what creating space looked like: liberating the patient from machines/technology, ensuring they had the things they would like (own blanket/clothes), the music they would like to listen to. We discussed the differences with working in the hospice, where they always meet the patient at the door when they arrive and walk them to the door when they have died, sometimes playing music (sometimes a song requested by the patient). Prof Vanderspank-Wright vividly recalled playing Dancing Queen (ABBA) on one occasion and how the family really appreciated this as they felt it was what their relative would have wanted. We discussed the importance of going the extra mile to ensure people felt cared for – Alicia Robblee recalled how on one occasion the ICU staff brought a patient's pet bird to stay in the ICU with the patient at the End of their life. I was guided to look at https://www.virtualhospice.ca/learninghub where there are modules to be undertaken by ICU staff

about grief and trauma on the ICU. I was also directed to useful resources about EoLC for the indigenous people of Canada. [96]

Figure 5. Critical Care (ICU) staff, the Ottawa Hospital ICU

EoLC in ICU in Canada certainly seems to benefit from dual training of intensive care doctors with palliative care medicine; several consultants (staff) are dual trained. This enables a wider view of EoLC and has enabled better working relationships between ICU and palliative care.

We discussed the impact of MAiD on palliative care and the impact this had on the ICU. It was noted that MAiD has raised national awareness around death and dying. And that on the whole it had not resulted in misunderstandings between MAiD and palliative care. They accepted that there were ongoing challenges and decisions to be made in this area – for example currently it is not possible to pre-consenting for MAiD, particularly when capacity may be later lost (for example when capacity may be lost at a future unknown point – such as with dementia). We discussed the change in mindset from being okay with the doctrine of double effect sometimes applied at the EoL to actually giving the medications needed for MAiD. We discussed the significant legal paperwork required for MAiD. We discussed that, disproportionately, white well-educated people opt for MAiD and how this might be viewed if it was a different intervention (for example Extracorporeal Membrane Oxygenation (ECMO)).

EoLC in ICU research

There is a significant volume of research looking at EoLC in ICU from Ottawa (and across Canada in general). We discussed the difference in doing a study for academic purposes verses the ability to improve EoLC for patients and the bereaved. There is difficulty in evidencing interventions through research as research is resource (time and people) intense. This difficulty results in people just doing things – for example the introduction of 3 wishes into their ICU, which may be a good thing, but lack of involvement of all stakeholders in the introduction of this and lack of evidence of benefits. We

discussed the difficulty in engaging bereaved families in research, and therefore understanding what would benefit them most isn't obvious. Bereaved needs aren't static either and what might help them (or what they say might help) can change from week to month and that some people are okay to engage at one time, but then not at another.

Prof Downar has surveyed bereaved relatives and found that the most common form of support requested by bereaved family members is an information session: an opportunity to simply review the events that took place in the ICU before the death. 58% of participants would have preferred to be followed up after the death, whereas 19% stated that they did not want to be followed up. [60] In this study they used a questionnaire for bereaved (ICG-r, SDI and bespoke) and staff (bespoke). There is no standard tool or timeframe for assessing the bereaved or for assessing staff willingness to be involved in bereavement research work. [111]

Key findings

1. Dual training in intensive care and palliative care is a good way to bring together these two specialties and improve EoLC in the adult ICU
2. Improvements in this area can be made through both improvement work and research. Collaboration is key to make these successful in practice
3. The context in terms of cultural, religious and public expectations around EoLC are different internationally and this needs to be considered when considering interventions in this area

France: Paris, Hôpital Saint-Louis

https://hopital-saintlouis.aphp.fr/

Figure 6. Sacre-Coeur, Paris

Context to EoLC in adult ICU in France

In France there are approximately 400 ICUs across 320 institutions. On average there are 10 beds in a French ICU (this is considerably smaller than in the UK). There is a robust legal framework governing and determining practice. An intensivist is required to be onsite at all times (this can be a junior with a senior on call from home). Unlike in the UK there is no required ratio for the number of intensivists/beds, for nursing staff the legal requirement is 2 nurses for 5 patients and 1 nurse assistant for 4 patients. [112] ICU mortality ranges from 15 to 25%. [113] In a 2016 study, open visiting for relatives was found to occur in 24% of units. [114] EoLC in French ICUs changed in 2016 with the introduction of the Claeys-Leonetti law to enable the practice of terminal sedation and to permit the cessation of useless treatments '*Acharnement therapeutique'* usually in agreement with the patient and/or their family, but with the overall responsibility lying with the senior physician. [115] Historically, France is one of the European countries which confers the least power to surrogate decision makers and has a relatively paternalistic way of practicing medicine. [116, 117] However, despite this national paternalism one of the largest EoLC in ICU (with a focus on family involvement) research groups is based in Paris, France – the Famirea group based at Hospital Saint Louis. Famirea is a multidisciplinary research group – their research is focused on the family experience of ICU, the experience of the patient and that of ICU staff. Famirea was created in 1996 by Elle Azoulay (an intensivist) and Frederic Pochard (a psychiatrist). Early studies described (through observation) the practices and experiences of those inside the ICU. More recently the group has developed tools to improve the support for ICU families such as booklets explaining the purpose of ICU and detailing bereavement support. Famirea has promoted research into family centred care in and across a network of ICUs.

Relevant studies by Famirea group

In 2000 Azoulay et al studied family experience of communication in one French ICU, this demonstrated that patients and families were more likely to poorly comprehend communication if the patient was: < 50 years old, unemployed, a haematology/oncology patient and/or if the relative was of foreign descent, a non-spouse family member and had no access to a healthcare professional in their family and/or if the Physician met the family for <10 minutes and did not give the family an information brochure. [118] A later Famirea multicentre study (2001) confirmed some of these findings, but also found that family satisfaction was improved where there were no perceived contradictions in information given by the clinical team, where patient to nurse ratio was less than or equal to three and sufficient time was spent giving information. [119] With regards to family involvement in EoLC in ICU, the Famirea group undertook a multicentre study in France in 2003 which found that although ICU clinicians were willing to invite families to take part in patient care, family members overall (66.6%) did not want to participate. [120]

A 2004 Famirea study looked at shared decision making in 78 French ICUs. They found that less than half of families wanted to be involved in shared decision making. [121] In 2005 the group undertook a review of European EoLC in ICU patients, they found that there was a need to develop cultural competency and the ability to adapt to patient and family needs. They also found there was a lack of communication with families and insufficient training in EoLC in ICU. [122] A 2007 study found that bereavement may be lessened by providing relatives with a bereavement brochure and enabling longer family meetings. [123] A 2009 multicentre (323 ICUs), multiple countries (24

countries) collaborative study found that EoLC, particularly lack of psychological support, lack of family meetings and difficulties in the decision-making process were a common cause of conflict in the ICU. [124] Several of the Famirea studies including a 2014 review article highlight the importance of involving families in EoLC decisions (shared decision making) and that information and communication from the ICU team are essential for this process to be successful. [125]

A 2015 Famirea study looked at complicated grief after the death of a relative in the ICU. This found 52% of relatives presented with complicated grief symptoms 6 months after the patient's death, which is a fivefold higher frequency compared with the general population. [126, 127] The risk factors for complicated grief were found to be: female sex, relative living alone, intensivist board certified before 2009, refusal of treatment, died while intubated, relatives present at time of death and that there was no opportunity to say goodbye. In 2016, the group undertook the CAESAR study; where they developed a tool to assess relatives' experience of dying and death in the ICU. This resulted in a 15-item questionnaire (named CAESAR), which includes the patient's preferences and values, interactions with/around the patient and family satisfaction. [128] In 2017 the group undertook a study looking at the effect of receiving a condolence letter on grief symptoms in bereaved ICU relatives. They found that a condolence letter did not improve grief symptoms and may have worsened depression and PTSD (as discussed earlier in this report). [70]

In 2018 the Famirea group developed a study protocol to guide intensivists' communication and behaviour towards bereaved relatives (the COSMIC-EOL study). This prospective, multicentre cluster randomised controlled trial study looked to assess the effectiveness of intensivist support for ICU families with a relative who was dying on the ICU. This study involved 3 meetings:

- Meeting one: Prepare family for imminent death and elicit understanding of situation
- Meeting two (room visit): Opportunity to express feelings and ask questions
- Meeting three: Post-death encounter (these meetings could take place within the hours following the patient's death, or when the relatives returned to the hospital the next day, or over the phone)

In this study the team (physicians and nurses) attended interactive educational meetings to set the importance of EoLC communication. These meetings were led by members of the Famirea research group and covered themes such as family experience in the ICU and their experience of EoLC, the impact of the ICU experience on bereaved relatives, communication in the EoLC context, what families recall 1 year after the patient's death and what caregivers can do to improve families' experience (and alleviate their burden). All caregivers received a leaflet about the importance of EoLC communication. Relatives were followed up by the Famirea research group using telephone interviews 1, 3, and 6 months after the death to complete the questionnaires. [129] The results of this study were published in the Lancet (2022) as 'a three-step support strategy for relatives of patients dying in the intensive care unit: a cluster randomised trial'. ICUs in France were involved in the study. The primary endpoint was the proportion of relatives with prolonged grief (measured with PG-13, score ≥30) 6 months after the death. They found that this strategy significantly reduced prolonged grief symptoms in families (from 21% to 15%, p=0.035). They commented that '*Communication could be one of the most important aspects of EoLC that needs improvement in ICUs'.* [130]

In a 2019 study the Famirea group aimed to explore the experience of bereaved relatives' participation in bereavement research (the ARREVE study, which included three telephone follow-

up calls to complete several quantitative tools). Three themes were derived from the thematic analysis:

- Struggling: reactivation of emotional distress associated with the ICU experience (particularly during the 1st follow-up call)
- Resilience: as time passes, research participation becomes increasingly positive, by giving meaning to the relatives' experience and in accepting the loss
- Recognition: research calls can compensate for the absence of support during bereavement

Additional findings from this study included feelings of guilt expressed by some relatives: '*Remembering that I had to make the decision and say "yes, now you can unplug the machine", since there was no longer any hope*.' [131]

In a recently published Famirea study (2024) Post Traumatic Stress Disorder (PTSD) was measured 90 days after ICU discharge using validated instruments (Impact of Event Scale and Impact of Event Scale-Revised) in >2000 family members. Risk factors for PTSD were found to include: spouse/child of younger patients (especially those receiving mechanical ventilation), being a female relative, longer length of ICU stay, genetic predisposition, personal history of mental health disorders, and family history of PTSD. [132] Another 2024 randomised controlled study published by the group looked at the use of ICU nurse facilitators to support and improve communication with 385 families of dying patients across 5 French ICUs. This study found that the use of nurse facilitators was not associated with a decrease of depression, anxiety or PTSD symptoms in families. [133]

Recurrent themes from papers:

- Communication issues between clinicians and families
    - Incomplete information
    - Poor quality information
    - Physician attitude (non-comforting)
    - Not listening
- Abandonment (lack of closure)
- Palliative care not always discussed
- Timing of bereavement support is crucial

Thoughts and questions prior to meeting

My main reasoning for this visit was to meet the Famirea team, especially Professor Elie Azoulay and Nancy Kentish-Barnes who have been prolific in researching and improving the experience of EoLC for families in ICU. I was interested to understand how this research was being used to to involve families in EoLC in clinical practice, to look at the provision of bereavement services available to ICU families and to speak to staff (and patient families) in the ICUs to understand how these methods work in practice. In addition, I was hoping to understand the differences between French and UK ICUs and to find out how they had developed and built their research team. Having reviewed their extensive research papers in this area I had several questions for them including:

- *What is it about ICU that causes relatives to develop complex grief?*

- *The communication strategy was presented using a video, which was followed by a discussion. What did clinicians feel about this study? What was the feedback? Were there any difficulties?*
- *Why doesn't a nurse facilitator improve grief outcomes?*

Individual and group discussions: Hôpital Saint-Louis, Famirea group

The Hôpital Saint-Louis is a small (650 bed) publicly funded hospital, which is run as part of the larger Assistence Publique – Hopitaux de Paris. The Hôpital Saint-Louis provides general and specialised (haematology, oncology, dermatology, infectious diseases and burns) care to patients in North-East Paris. The original building was built in 1605-1606 to look after patients from the plague epidemic. Hôpital Saint-Louis employes approximately 2500 people and is therefore considerably smaller than UCLH (>11,500 staff). They currently do not have electronic health records. The ICU is relatively small (total 20 beds), they have 10 level 3 beds, 6 level 2 beds and 4 renal dialysis beds. They admit medical patients (there is a separate surgical ICU run by anaesthetists). The occupancy rate is much lower than in NHS ICUs at 80%, there are usually 1 to 3 admissions in 24 hours. Their mortality rates from a study in 2018 found 22% of patients died in the ICU. Of those that survived a further 21% were dead at one year follow-up. [2] Hôpital Saint-Louis ICU has full open visiting for all families regardless of the prognosis for the patients.

Figure 7. Hôpital Saint-Louis, Paris

The ICU at the Hôpital Saint Louis is relatively dark with stark lighting. The relative waiting area is a set of chairs by the reception desk. There is a windowless room where people can sleep overnight next to the reception. The nursing ratio for intubated patients is 1:3, the nurse is assisted by 2 nursing assistants. In view of the nursing ratios, to prevent inadvertent extubation, patients are

physically restrained (arms are shackled to bed rails). The doctor-patient/family relationship is more paternalistic than in the UK. Decisions about significant changes in care, especially EoLC, withdrawal, limitations in treatment are made by consensus of at least 3 consultants and then relayed to the family as a consensus opinion. It is a legal requirement that this type of decision is made by more than one consultant (legal framework for group decision making).

Over three days I met multiple colleagues including: Prof Elie Azoulay (Professor in Intensive Care Medicine), Nancy Kentish-Barnes (Sociologist), Frédéric Pochard (Consultant Psychiatrist), Anne Renet (Psychologist 50:50 clinical and research), Virginie Souppart (Nurse Facilitator both ICU nurse > 20 years and researcher) and Virginie Lemiale (Consultant Intensivist). Within the ICU I saw ICU patients with families and staff working (doctors rounding, nurses caring for patients). I did not have the opportunity to speak to any families during this visit as there was no-one suitable.

Some of the topics covered during my visit included:

- **Methods and interventions used to involve families in EoLC**
    - 24/7 open visiting
    - Psychology support for families and staff
    - MDT approach to remind staff of the difficulties for the patient and the family
    - Interventions (such as the through the nurse facilitator role, the 3 step communication strategy)
- **The provision of bereavement services available to families**
    - Bereavement leaflet
    - Interventions
- **How these methods work in practice**
    - Use the research agenda to improve practice
    - Ongoing input from MDT (psychology and nurse facilitators in particular)
- **EoLC in ICU research**
    - Very research driven

Methods and interventions used to involve families in EoLC

There is a strong belief in the benefit of a 24/7 open visiting for families. Since nursing isn't 1:1 having family there all the time is less intense for the bedside nurses. The current facilities (waiting, resting, sleeping) for families are due to be revamped and improved in the coming months. The MDT approach is considerate to families, and they appear to be continually looking for ways to improve on what they are doing.

The role of the psychologist is fully integrated into the ICU team (Anne, has been at Hôpital Saint-Louis for more than 5 years). They support the team to do their job better, being there to remind staff of the difficulties for the patient and the family and to enable staff to reflect on their roles and impact on families. Anne and Virginie (a nurse facilitator) help oversee a person-centred culture on the ICU. The psychology role in ICU in France, not everywhere (approximately 20 to 30% of units have a psychologist).

The nurse facilitator role (undertaken by 4 nurses including Virginie S) was created as part of one of their research studies [133]. Unfortunately, as the study did not demonstrate any measurable

benefit for this role it is no longer officially in place. However, unofficially Virginie S continues to provide support to families (even when she is not at work) and she feels that there is a benefit of providing this support for these families. She sees her role as preparing the family for the end of their relative's life and adapts this to each family. She also noted that although their ICU does not offer any specific mementos for relatives, she will where possible make their requests happen.

The communication strategy used in their 2018 study was still being used in practice where possible at Hôpital Saint-Louis, with an emphasis on group (consultant) decision making and then communication with the family. [130] The Famirea research group are currently undertaking qualitative work to better understand how participating clinicians felt about undertaking this intervention. Virginie S told us that part of her role is to encourage clinicians to undertake all 3 steps.

The provision of bereavement services available to families

Bereavement services in Hôpital Saint-Louis ICU are again driven by research findings through the work of the Famirea group. There is an information leaflet that is given to families (figure 8) and families are often invited to be involved in research which may provide bereavement support. [131]

Figure 8. Hopital Saint-Louis ICU patient information leaflet

With Nancy Kentish-Barnes, Virginie Souppart, Anne Renet and Frederic Pochard we discussed what they thought is it about ICU that causes relatives to develop complex grief. They felt that some of it was due to pre-existing problems (PTSD, depression, anxiety) and due to a loss of control that comes with relatives being in ICU. The risk factors for post-ICU PTSD may have been there long before the patient (and family) ever came to the ICU. We also discussed the possibility that some of the PTSD comes after leaving ICU through a sense of abandonment. We discussed if they thought background

(non-ICU) grief and bereavement may have changed since most of the studies were done in the 1990s – they thought that this could be the case.

We also discussed why some of their studies showed unexpected results (for example the condolence letter worsening grief symptoms), [70] they felt that this may have been related to the timing of when the symptoms were measured. A subsequent qualitative study (from 2017) found that receiving a condolence letter enabled relatives to feel supported and provided closure. [134]

EoLC in ICU research

The Famirea research group are prolific and dedicated to their research agenda. They have without doubt through their research raised the profile of EoLC in the ICU both nationally (in France) and internationally.

Key findings

1. Improving communication particularly between intensivists and families is the key intervention
2. Research shines a light on family involvement in EoLC in ICU, but deliberate ongoing implementation is needed to ensure clinical benefits
3. Ways of working have some significant differences to UK ICUs; context is important when interpreting research findings

Findings from virtual meetings

Netherlands: Leeuwarden, Medisch Centrum Leeuwarden

https://www.mcl.nl/

Context to EoLC in adult ICU in the Netherlands

The Dutch Termination of Life and Assisted Suicide law has been in place since 2002. Along with Belgium, the Netherlands was the first country to introduce assisted dying into law. [135] Specific conditions (such as unbearable patient suffering with no prospect of improvement) must be met before assisted death can lawfully be undertaken. [136] By 2015, 4.6% of all deaths in the Netherlands were people who had undergone assisted dying. [137] The Dutch Association for Intensive Care (NVIC) produced guidelines with regards to EoLC in the ICU in 2021, this includes sections on the legal and moral frameworks for EoLC in ICU, guidance on withdrawal of mechanical ventilation and a checklist for EoL decisions. [138] There was further guidance in 2022, specifically for intercultural EoLC in the ICU. [139]

Several EoLC in ICU studies have been led by Dutch ICU clinicians. A group in Tilburg have undertaken studies looking at bereavement care. Their systematic review in 2022 had similar findings to Efstathiou et al, 2019 and Moss et al, 2021; that a communication strategy, EoLC/bereavement brochure, a condolence card and telephone call from the hospital may reduce grief symptoms. [68, 72, 140] The Tilburg group also undertook a cross-sectional single site study evaluating the quality of ICU EoLC and bereavement support strategies. They found overall the quality of care was good, with improvements identified including increased bedside presence of clinicians, better consistency and quality of information. They also found that families found bereavement calls 2-3 months after the death beneficial. [141]

Dr Rik Gerritsen, an intensivist in the Netherlands (since 1998), has a research interest in EoLC in ICU. He works in the ICU at the Medical Centre Leeuwarden. This is a 20 bed ICU with mixed medical and surgical patients (including transplantation, trauma, neurosurgery and cardiothoracics). In 2013 he published findings from a study looking at the perceptions of family members and ICU staff with regards to the quality of death and dying in the ICU in 3 hospitals in the Netherlands using the Quality of Death and Dying (QODD) questionnaire. This found that families were satisfied with the overall QODD, felt supported by the clinical team and that they were involved in decision-making. This study also showed that family members found the QODD questionnaire difficult to complete. [142] This study was the first in a series of studies for Dr Gerritsen's PhD (2018), which looked at 'Measuring satisfaction with general and EoLC in the ICU'. The outcomes from this included development and validation of the euroQ2 questionnaire. [143, 144, 145]

Thoughts and questions prior to meeting

I was keen to discuss how families are involved in ICU care in practice and what bereavement support they are currently offering. I wanted to try to understand how shared decision making occurs and whether they experienced much conflict with families around EoLC. I also wanted to explore how they were hoping to improve EoLC further in the future.

Individual online discussion: Dr Rik Gerritsen, Medisch Centrum Leeuwarden

We discussed the patient mix of the ICU at Medisch Centrum Leeuwarden and that most patients coming to the hospital live in the surrounding area. They have two patients per bay, the majority of patients are ventilated and therefore predominantly they have 1:1 nursing ratios. They try not to sedate where possible and therefore 1:1 nursing is important for them. They don't have set visiting times at the hospital, it is open access, although families are advised not to come in the mornings (when rounds are happening). Families are invited to help in daily care and the last rites when a person dies. They don't have palliative care as a separate specialty in the Netherlands, palliative care is an integral part of healthcare and therefore intensivists are trained for and undertake all EoLC. In the community GPs look after EoL/palliative patients. [146]

Dr Gerritsen highlighted the importance of family centred care in the Netherlands and at their hospital. With regards to shared decision making, they discuss EoL concerns with families, but ultimately most of the decision making is clinically made and needs to be carefully communicated to the family. There are low levels of conflict between families and healthcare staff. Dr Gerritsen felt this is related to shared beliefs and values with much of the local population (they have little difficulty communicating with families as most people speak Dutch). In their experience they have found that conversations are sometimes more difficult where patients/families are non-western immigrants. We discussed that there is some variation between different regions/hospitals and Consultants in the Netherlands (like all countries).

They have bereavement follow up as standard in their ICU. They call families at 6 weeks post death (family aware at the time of death that they will be called). As part of this they have psychologists to assist in providing bereavement support. They also have a remembrance ceremony for those that have died.

We discussed all the improvements they have made to improve family experience (in general and for EoLC):

- Unrestricted access to patient
- Comfortable family room
- Chance to participate in physical care (offered the choice)
- To reassure families that loved ones will not suffer
- Frequent and open communication throughout the stay, building up the conversation about withdrawal
- Explaining what will happen (prepare the family for dying)

With regards to what they would like to do to improve further, Dr Gerritsen felt that they do not do enough to provide spiritual support and could do more in this area.

Key findings

1. Good EoLC can be provided without a dedicated palliative care service if the right training and resources are available
2. Frequent and open communication are important in ICU EoLC

USA: Vermont, The University of Vermont Health Network

https://www.uvmhealth.org/

Context to EoLC in adult ICU in the USA

The United States of America (USA) has a very different healthcare system when compared to the UK. It does not provide universal healthcare. Healthcare is largely provided by the private sector and paid for through a combination of insurance, public schemes and at individual expense. [147] ICU beds account for 20% of all healthcare costs. Dying in the ICU in the USA is expensive. Despite this, 20% of Americans will die in the ICU, sometimes in pain receiving care they might not choose. [148] Despite these difficulties much of the early EoLC in ICU research and college/society guidance was from the USA.

In 2008, the American College of Critical Care Medicine published a statement of recommendations for EoLC in the ICU, many of which are based on USA court cases (from 1914 to 1990): [25, 26]

- Competent patients have the right to determine how their bodies can be used, and that informed consent is required for therapeutic interventions
- Competent patients have the right to refuse interventions that, if they became incompetent, decision making could be delegated to surrogate decision makers
- Surrogates could refuse all interventions on behalf of patients based on a benefit-burden analysis
- Lacking surrogate knowledge of patient wishes, decisions could be made using best interests' standards if the burdens of interventions outweigh the benefits and if the pain of living is such that administering the intervention is considered to be inhumane
- Individual states are allowed to set the level of evidence to determine the prior wishes of incompetent patients

Palliative care has only been formally recognised by the American College of Graduate Medical Education as a subspecialty since 2006. [149] Palliative care is provided in most American ICUs as a mixed integrative (where EoLC within ICUs is provided by intensivists) and consultative (where palliative care specialists provide EoLC within ICUs) approach. [150] This is like the UK approach. Where palliative care specialists attend ICU it is essential that a collaborative joined up approach is fostered. Without this family may experience worse post traumatic stress. [151]

In 2015 several American medical societies in conjunction with the European society of Intensive Care Medicine defined 4 key recommendations for requests for potentially inappropriate ICU treatment: [152]

- Early strategies should be implemented by institutions to prevent treatment conflicts through communication and expert consultation
- Use of 'potentially inappropriate' rather than 'futile', where clinicians believe ethical considerations outweigh benefits to providing certain treatments. Where conflict arises around 'potentially inappropriate treatments' a conflict resolution process should be followed
- 'Futile' should be used only where it is clear interventions can't meet intended physiological goals

- Medical professional engagement with the public to discuss when life-prolonging technologies shouldn't be used and promote policy development and legislation in this area

A 2019 study by Kruser et al, assessed the variability in EoLC in American ICUs. They found EoLC varied significantly between units when looking at pain, delirium, rates of cardiopulmonary resuscitation in the last hour of life, open visitation policy and the offer of spiritual support. [153]

A 2023 conference paper, with Randall Curtis as the senior author, looked at predictors of family satisfaction with decision making for patients who die. They found higher satisfaction when the patient who died was older, a do not resuscitate order had been placed and spiritual support was provided. [154]

In the past 20 to 30 years there has been much interest across American healthcare professionals in researching EoLC in the intensive care setting. Notable researchers in this area include Randall Curtis (University of Washington), Doug White (University of Pittsburg), Derek Angus (University of Pittsburg) and Rebecca Aslakson (University of Vermont). Prof Randall Curtis, who dedicated much of his working life improving EoLC in the adult ICU unfortunately died on the 6th of February 2023. I had originally planned on visiting him within this Fellowship. His obituary (in the Lancet) stated '*Curtis felt that patients in intensive care units (ICU) were too often treated as failing organisms rather than sick people who, along with their families, also needed other forms of close attention*'. [155] I have instead met with Prof Rebecca Aslakson, who collaborated with Prof Curtis and has also individually made significant contributions to this field.

Rebecca Aslakson is dual trained as a fellow with both the American Academy of Hospice and Palliative Medicine and the American College of Critical Care Medicine. She was based at Stanford University until 2022 when she moved to become Chair of the Department of Anaesthesiology at the University of Vermont. Her research investigates patient centred, family centred and palliative care in perioperative and critical care medicine. Her 2013 PhD thesis was titled 'Palliative care and communication regarding prognosis in the Intensive Care Unit', in which she reviewed ICU based palliative care interventions. Her findings included that a consultative approach reduced length of stay without impacting patient or family satisfaction and that interventions need to be sensitive to practical and cultural barriers to ICU based palliative care. [156] In 2022 Prof Aslakson wrote an editorial titled '*chuck the old compass for a new one: Navigating palliative care in the ICU*', in which she describes the need to look for more specific and targeted interventions to support families of palliative ICU patients, such as financial support. [157]

Thoughts and questions prior to meeting

Prior to meeting Prof Aslakson, I watched a YouTube video made of one of her talks from 2018 '*Palliative care for Perioperative Populations*'. [158] In this talk she describes why she became interested in EoLC in the ICU and describes a complex patient whom she cared for as an example of one of the 10% of ICU patients who take up 40% of resources and 80-90% of emotional/mental bandwidth. She described the different facets to palliative care: symptom management, psychosocial support of family, compassion and communication. And the importance of palliative care not just went people are dying, but also when they are suffering (to improve quality of life).

Prof Aslakson explains that ICU teams are not good at recognising who might die and the importance of finding balance between curative and restorative care, and palliative care.

Watching this video improved my understanding of Prof Aslakson's perspective and research, which resonated with my own experiences and interests. In view of this I wanted to find out more about dual training in palliative care and intensive care medicine, about managing conflict with families when differences in opinion arise, her PhD thesis findings and which interventions she thinks are most beneficial to EoLC in ICU patients and their families.

Individual online discussion: Prof Rebecca Aslakson, The University of Vermont Health Network

We discussed the differences in the UK and USA healthcare systems, but also the similarities around some of the ways in which EoLC in ICU has developed (as mixed integrative/consultative approaches).

We discussed several research studies that had demonstrated the benefit of early palliative care involvement in patients with both improving quality of life and duration of survival. [159] We also discussed the value of hope and that hope isn't necessarily diminished in those who are told they are unlikely to survive. [160] We discussed that dual training with palliative care and intensive care medicine isn't really an option in the UK. In the USA, you can only apply for palliative care fellowships every other year (and the places are very limited). This will hopefully change in the USA with the passing of new legislation in 2019, the 'Palliative Care and Hospice Education and Training Act'.

Prof Aslakson discussed that her PhD research is based on trying to do better by patients: supporting patients and families in ICU and beyond, aiming to improve palliative care in the ICU and perioperative settings. Her thesis consists of 3 parts: 1) a systematic review of palliative care-related interventions in adult ICUs, 2) a cross-sectional survey of surgical critical care provider perceptions regarding adequacy of communication concerning prognosis for long-stay patients and their family members, and 3) a pilot study of a structured communication intervention for long-stay surgical critical care patients and their families. Interventions described from the systematic review include: ethics consultations, intensive multidisciplinary communication with ICU team members, informational brochures/booklets, palliative care consultative or integrated care consultations, palliative care-related clinician education, structured communication with either an ICU nurse or social worker, family coordinator involvement, use of local champions, a palliative care team member rounding with the ICU team, trigger systems indicating a patient to be appropriate for palliative care consultation, individual clinician feedback and standardised palliative-care related order sets or symptom scoring (interventions were often comprised of multiple components, which is likely to be the most effective approach). The piloted communication intervention did not make any significant difference. More recent research undertaken by Prof Aslakson and team have found that expectations of family members of patients following high risk surgery do not match actual outcomes; families think that the patient will either do well or will die. Not that they will be in an in between state where they are unwell for months and months often in the ICU (and then sometimes die).

We discussed how she manages conflict when the family do not agree that the patient is approaching the EoL and that certain treatments should not be started or withdrawn. She advised that there will always be families that disagree, but that this is the minority. Good consistent communication is important but can't always influence or make the complete difference in these families. She discussed a recent study where patients and families were invited to make Advanced Care Plans (ACPs) before high-risk surgery and that in this study they had found patients/families who were in the intervention arm of the study (and therefore made ACPs) were keen to do the ACPs and that there were more patient/family conversations in this arm.

Prof Aslakson explained that future studies should address better systems to arrange EoLC meetings on the ICU and to ensure that pertinent topics are reliably and appropriately addressed during these meetings.

Key findings

1. Finding the right approach (integrative vs consultative) is unit dependent and a mixed approach is probably best
2. A multi-intervention approach is probably optimal for improving EoLC in ICU patients
3. Sometimes conflict with families is unavoidable

New Zealand: Health New Zealand Capital, Coast and Hutt Valley: Wellington/Hutt

Context to EoLC in adult ICU in New Zealand

In 2003, the Australian and New Zealand Intensive Care Society (ANZICS) published a 2-page document called the 'ANZICS Statement on Withholding and Withdrawing Treatment', designed to provide a principle-based best practice in the care of critically ill patients at the EoL. This early progressive work has been developed subsequently with furthermore extensive guidance (including ethical and legal guidance): *'ANZICs statement on Care and Decision-Making at the End of Life for the Critically Ill'* published in 2014. [161]

A 2022 study published in the New Zealand (NZ) Medical Journal looked at the outcomes of patients admitted to NZ ICUs between 2009 and 2018. They found a difference in 180 days from admission mortality for Maori (16.0%) and European (14.9%) patients, despite a younger average age of Maori patients (13 years younger) admitted to ICU. [162] Maori people (and others) have specific cultural, social and spiritual needs associated with death and dying. A 2023 study (Taylor et al) highlights the importance of '*Whanaungatangu*' (relationships, kinship, connections and belonging) in Maori EoLC in the ICU and also described a lack of cultural education amongst healthcare staff. [163]

In late 2019, the New Zealand parliament voted in favour of legalizing assisted dying and in 2020 a national referendum on the issue took place. This resulted in the legalisation of assisted dying from November 2021 through the End-of-Life Choice Act. [164]

Despite the early work undertaken by ANZICs, there appears to be less research on EoLC in ICU from NZ, perhaps due to the smaller size (and population) of the country. There is some research and improvement work from Wellington Hospital in NZ, including from Dr Alex Psirides, an ICU consultant who has an interest in EoLC in ICU who has spoken at international meetings (such as SMACC 2019) about the reluctance of society (and doctors) to talk about death and the importance of having EoL conversations with families. [165] In an attempt to get a broader understanding of EoLC in ICU at other hospitals in New Zealand I spoke to a palliative care consultant at Hutt Hospital, Dr Tom Middlemiss. Both Dr Psirides and Dr Middlemiss have worked in their given specialties in the UK.

Thoughts and questions prior to meeting

I wanted to find out about the interactions between palliative and intensive care medicine in these two different hospitals and to better understand the differences where they arise:

- To understand from physicians who have worked in both the UK and in NZ what the cultural differences are in the approach to EoLC in ICU
- To understand examples of where and how families are involved in EoLC in ICU

Individual online discussion: Dr Tom Middlemiss, Hutt Hospital

Hutt Hospital is in the Welllington region of the North Island, along with Wellington Hospital it is part of Capital, Coast and Valley district. Hutt Hospital is relatively small with a total of 322 inpatient beds and 6 ICU beds. When I met with Tom Middlemiss we discussed that historically the palliative care team there haven't had much involvement in EoLC in the ICU, but that this had changed over the last few years with the recruitment of new intensivists (who have possibly trained in environments where this is commonplace). Dr Middlemiss discussed the set-up of palliative care in NZ and explained that bereavement services are provided by community teams and not from hospitals. Dr Middlemiss recommended the national document 'Te Ara Whakapiri' (2017), provides EoLC guidance for hospitals and hospices. [166] We discussed the importance of cultural consideration in NZ to respect the differing values and beliefs of Maori people and European/Western beliefs. Dr Middlemiss highlighted the importance of cultural safety, building connections (looking for connections) and being a cultural advocate (to ensure offered care services and to improve equity). [167]

Group online discussion: Dr Alex Psrides, Dr Emma Mcmenamin (Palliative Care Consultant) and Cherie Watts (ICU and Palliative Care specialist nurse), Wellington Hospital

Wellington Hospital is a larger hospital, with 496 inpatient beds. They have a mixed (adult/paeds) tertiary ICU admitting approximately 2000 patients a year through 24 beds. They have a tertiary catchment population of around 1 million for the upper South and lower North island. About 75% of admissions are unplanned/acute. In-ICU mortality is approximately 8-9% (160-180 deaths per year). Dr Psirides advised that historically palliative care as a specialty has not been involved as part

of the wider approach of EoLC in ICUs in Australia and NZ, but that in Wellington Hospital they work closely and have a strong relationship with the palliative care team. Although it is not common to dual train in ICM and palliative care they thought that there is at least one dual trained Consultant working in the Hawkes Bay region. A study undertaken by Dr Psirides in 2009 suggested a wide disparity between belief and practice, with variable documentation regarding end-of-life decision-making and treatment of patients for palliation in the ICU. The ICU team in Wellington recommend a standardised approach to improve communication between medical and nursing staff. [168] The ICU team at Wellington Hospital is actively encouraging other hospital ICUs to take part in EoLC in ICU and they are trying to share their experience at conferences.

They discussed that a significant proportion of critical care admissions are Maori people of NZ and that families often request for cultural and religious reasons, to take patients home to die. Dr Psirides commented that the ICU department recognises the long-lasting impact of interactions with healthcare, NOT just with ICU, and the importance of maintaining good relationships with patients and families.

Wellington ICU have several standard practices that ensure patients and families are involved in EoLC in their ICU:

- Goals of care are discussed (Treatment Escalation Plan)
- Involvement of psychology is important
- They recognise the importance of being culturally competent
- They have had open visiting since 2015 (as result of 2015 local study they did interviewing relatives)
- A specialist nurse in both ICM and palliative care medicine (provides educational and cross-collaboration benefits)

As an example of cultural competence, to enable the strong Maori belief in the importance of being at home to die, the ICU team often facilitate the transport of patients (from all backgrounds) home to make this happen, if this is what the patient and family want. This has been a long-standing practice of the ICU team in Wellington and was described in detail in a 2005 article by Michelle Ryder-Lewis, an ICU specialist nurse in their team. [169] This service involves a flight coordinator (usually an ICU nurse) and supports 9 hospitals across the North and South Islands. The team involve the local palliative care team to ensure a smooth transition to community care (with a transfer of care policy). The ICU team have a final meeting with the family prior to departure from the hospital to ensure expectations are set, such as extubation in the home and what this may entail. Dr Psirides explained that there is a '*can do'* attitude in NZ which facilitates this. They work hard to reduce any physical barriers (for example on one occasion they built a temporary ramp to access a patient's house). They also advised me that the ambulance service are very flexible and compassionate, for example taking the patient to the beach on the way home.

With regards to bereavement support, families are sent a bereavement letter and offered a bereavement call. Approximately 20% take this up and it is usually utilised by families for tying up loose ends: to meet the consultant in person, to gain answers to questions about what happened, to better understand events. They have found the ability to do this is important to families, it also helps improve (change) practice and they believe it also reduce complaints. The ICU department

undertakes the Morbidity and Mortality review before the bereavement phone call to help inform the conversation with the family. They have been undertaking bereavement follow-up since 2001. Bereavement follow-up is not a funded service. Dr McMenamin discussed multiple bereavement services available to signpost families to if needed:

- Skylight – a bereavement resource (especially for people with children)
- Kenzies gift – offers bereavement support
- Catholic bereavement services (open to people of all faiths and non-faiths)

The palliative care team, oncology team and general medical teams at Wellington Hospital send bereavement cards within a week of the person's death as standard. The palliative care team doesn't often offer bereavement support from within the hospital team.

Dr McMenamin discussed some of the differences in perception in ICU – for example, for intensivists 36 hours seems like a long time, but for palliative care physicians this is relatively short. She has also found that there is a high desire to be accurate in ICU and a surprising difficulty for intensivists in predicting death.

Key findings

1. Improvement in involving families in EoLC in the ICU can be made without research programmes (and research funding)
2. Collaboration, leadership and engagement from staff to make improvements enables better EoLC for families
3. Improving EoLC for specific (often disadvantaged) groups can enable improvements for all patients and their families

Conclusion

The involvement of families in EoLC in adult intensive care and the provision of bereavement services to these families varies around the world. Through this Fellowship I have found that the hospitals where improving the involvement of families and the provision of EoLC in adult intensive care is prioritised have these three commonalities:

- Clinical staff who are leading or driving this agenda – whether through research or improvement initiatives
- A compassionate, relatively cohesive and often collaborative multiprofessional approach to patients and their families with a willingness to listen, learn and adapt
- Family communication which is open and honest, sets expectations and manages uncertainty

This Fellowship has been instrumental in enabling me to reflect on the involvement of families in EoLC and the provision of bereavement services to these families at my hospital. It has made me consider why we do certain things (such as restrict visiting times) and why we don't do other things (such as routinely conferring with other consultants when withdrawing or limiting treatment). I have found that how support is provided (the methods and/or interventions) or by whom can vary and that no one way is '*the right way*' to do this. For example, some units opt for palliative care involvement, whereas others have a bigger input from psychology and/or social workers. Another example of this is how in Ottawa they have used the 'Three Wishes' initiative, whereas in Paris they simply ask families what their wishes are as standard when a patient is EoL. Overall, I have found that the provision of bereavement services for bereaved families is mostly underprovided. I have found that positive interpersonal relationships and multiprofessional teamwork are universally important. I have found that understanding what is important to families including the cultural and religious beliefs of the patient is important when providing EoLC and have seen that improving care for minority groups can open up benefits and possibilities for all. For example, getting Maori patients home to die in New Zealand.

During my visits I was not able to speak directly to families about their experience of involvement in EoLC and bereavement follow up as this did not seem appropriate at the time of these visits. While this was one of my aims which has not been met I have been able to review feedback from relatives involved in research studies and gained insights from the staff who have worked with these families.

Improvement at UCLH and within the NHS more broadly could be achieved through the following:

- Development of best practice guidance around EoLC in adult intensive care for UCLH
    - Guidance on family involvement and the provision of bereavement services
    - Prioritising EoLC training for intensive care trainees
- Better understanding of cultural and religious needs of our patients
- Caution in applying findings from international EoLC research studies, where the context of their ICUs and working practices may be significantly different
- Consideration around language used in EoLC planning: goals of care (not Treatment Escalation Plan)
- Identifying if there is a need for bereavement support (locally and nationally)

- Consideration for what bereavement support should look like (locally and nationally)
- Formation of a multiprofessional research and/or improvement group for EoLC in adult intensive care in the UK with greater participation in EoLC research studies
- Better understanding of risk factors for conflict with families where the patient is EoL and how these can be mitigated
- Better understanding of uncertainty in EoLC and how this can be managed
- Better understanding of the best ways to communicate with and listen to families to explain treatment escalation and the nature of dying

The value of this Fellowship will continue; where I visited countries in person and even where meetings were held online, I have been able to form connections with clinicians for future collaborations. Several of the individuals whom I have been fortunate enough to meet have indicated that they would like to visit UCLH to view our management of EoLC in adult intensive care and I would be more than happy to facilitate this.

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