Where are we now and what's in the future?

A research and practice update for palliative and end-of-life care in critical care

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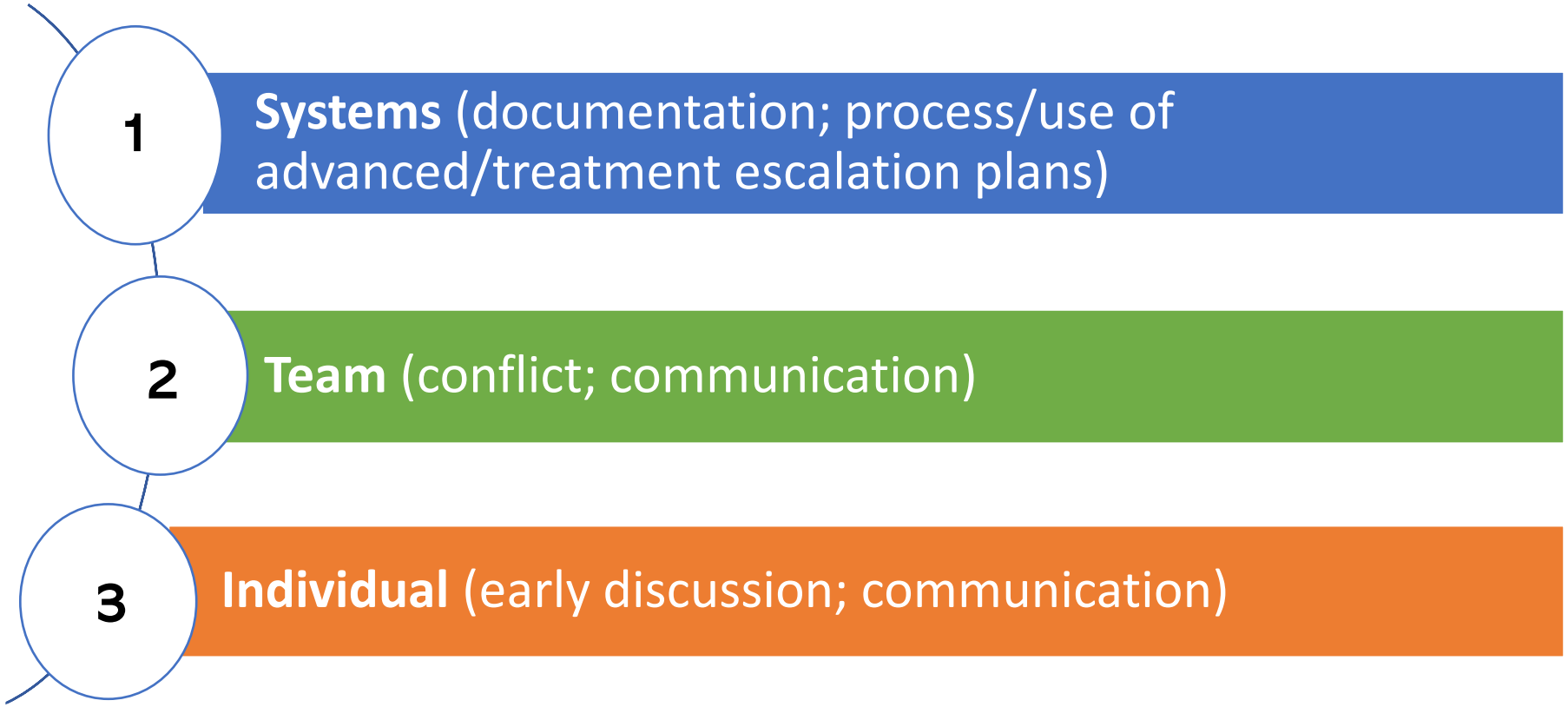
Overview

- Communication and end-of-life decisions
- Symptoms in ICU and palliative/end-of-life Interventions
- Bereavement
- Implementation – research into practice
- Where should we focus future work?

Communication and end-of-life decisions

Broad headlines: what do we know…?

- Failures occur at:



1 **Systems** (documentation; process/use of advanced/treatment escalation plans)

There are system level problems in the UK in terms of infrastructure: bed availability; staffing; cultural adaptation; ability to transfer out of unit to die; resources. Lack of cultural sensitivity.

Structured discussion at the time of acute admission to hospital and review by specialist teams at the point of an acute deterioration (Field R et al 2014 Resus 85:1418-)

Timing

ICU environment

Parent medical team

Cultural sensitivity (Brooks M et al Aus Crit Care. 2019 32:516-)

2 **Team** (conflict; communication)

- **Failure to address ACP early enough in the person's illness trajectory, or when well**
- **Climate difficult to influence – measuring for research more difficult**
- **Shared decision-making impact**

  - Different expectations and preferences between clinicians and pts/rels toward DM, influenced by religion, race, culture, and geography. (Frost DW et al 2011 CCM 39:1174-)

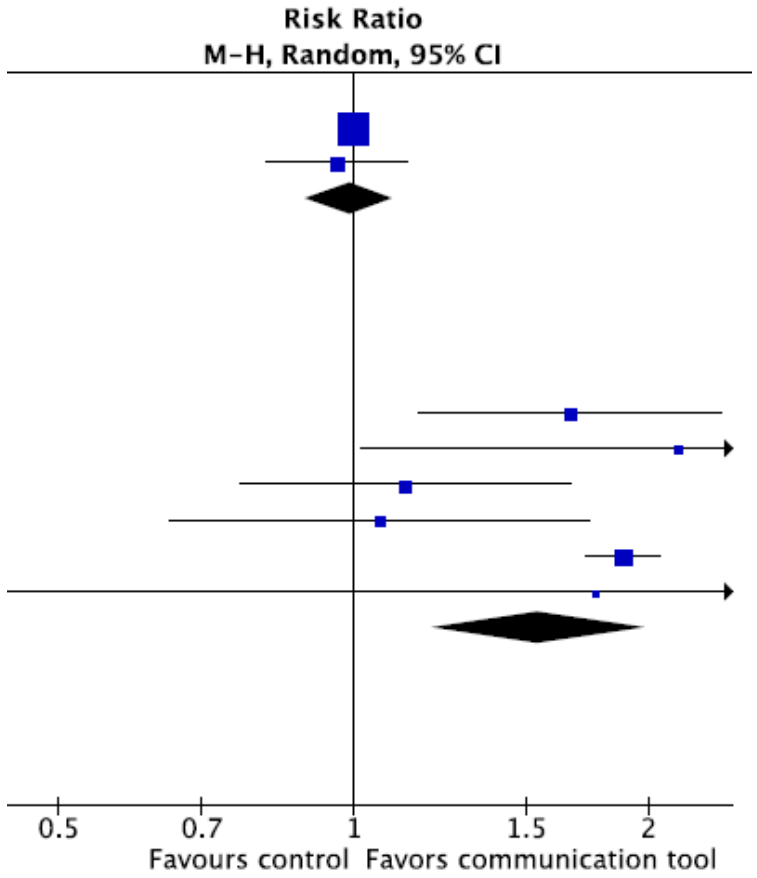
  - Few studies evaluated interventions to improve communication in DM between HCPs and patients/families. Interventions that include essential elements of shared DM need greater evaluation – but ↓ family anxiety/distress and reduced LOS.(Kryworuchko J et al 2013 World Evid Based Nurs. 10:3-; Hajizadeh et al 2016 MDM Policy and Practice 1: 238-)

3

Individual (early discussion; communication)

- Is multi-modal training needed (case study, sim/role play, self-reflection)? **Sim alone not enough** to translate into practice (Curtis JR et al 2013 JAMA 310:2271-)

- **Tools for EOL DM** – enhancing literacy/quality of communication/DNACPR documentation (Oczkowski S et al 2016 Crit Care 20:97)

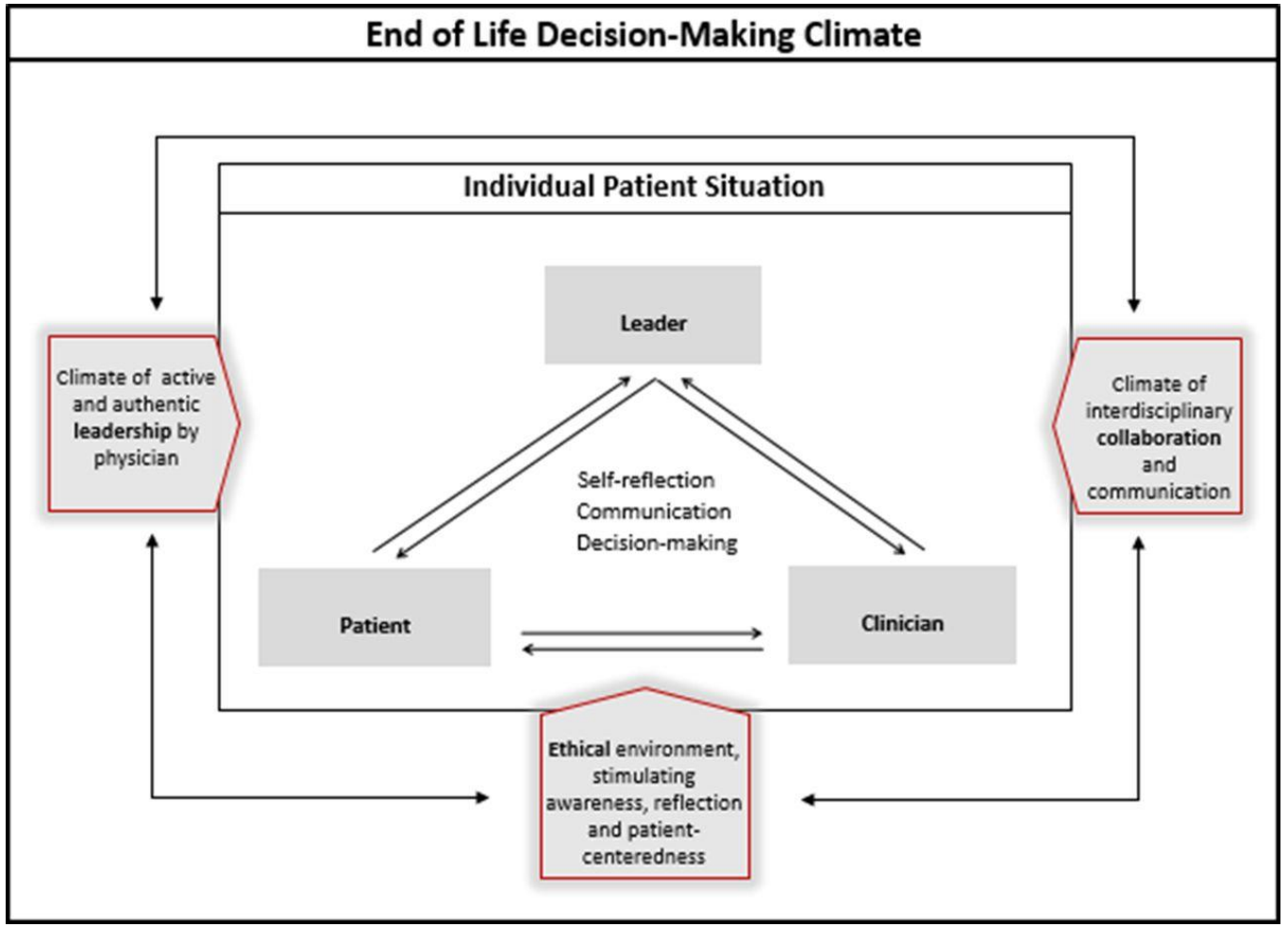


Working out who should be involved?

Organisation /Structure

- What is the **ethical climate**? (Van den Bulcke et al, 2018 BMJ Qual Saf, 27:781-)
- What opportunities are there for **reflection and support**?
- Prevention of burnout (Pattison et al 2019 NICC 25:93)
- **Family and patient**
- **Continuity of nursing care**

  (Kruser et al 2019, JAMA Netw Open. 2(12): e1917344)



What's the evidence for tools in ICU?

Should structured communication tools for end-of-life decision making be used in adult intensive care units?

Outcome № of participants (studies)	Relative effect (95% CI)	Anticipated absolute effects (95% CI)			Quality
		Without structured communication tools	With structured commu-nication tools	Difference	
Proportion of patients/families with documented or reported goals of care discussion № of participants: 1229 (4 observational studies)	**RR 3.47** (1.55 to 7.75)	**Study population**			⨁◯◯◯ VERY LOW [1] [2]
		249 per 1000	**863 per 1000** (385 to 1000)	**614 more per 1000** (137 more to 1678 more)	
Proportion of patients with preferred or documented DNR status № of participants: 1149 (2 RCTs)	**RR 1.04** (0.90 to 1.20)	**Study population**			⨁⨁◯◯ LOW [3] [4]
		728 per 1000	**750 per 1000** (699 to 801)	**22 more per 1000** (29 fewer to 73 more)	
Proportion of patients with	**RR 0.99**	**Study population**			⨁⨁◯◯
documented decision to withhold or withdraw life-sustaining treatments № of participants: 1205 (2 RCTs)	(0.89 to 1.10)	756 per 1000	**741 per 1000** (673 to 817)	**15 fewer per 1000** (83 fewer to 61 more)	LOW [4] [5]

Also very low quality of evidence

- Satisfaction
- Quality of Communication
- Literacy
- Health care utilisation
- Length of Stay (ICU and Hospital)
- Ventilator use

Oczkowski et al 2016 Critical Care 20:97 – Pignatiello et al 2018 W J Nurs Res 40:84-

End-of-life care in critical care

Symptom assessment/ management

Process of withdrawal

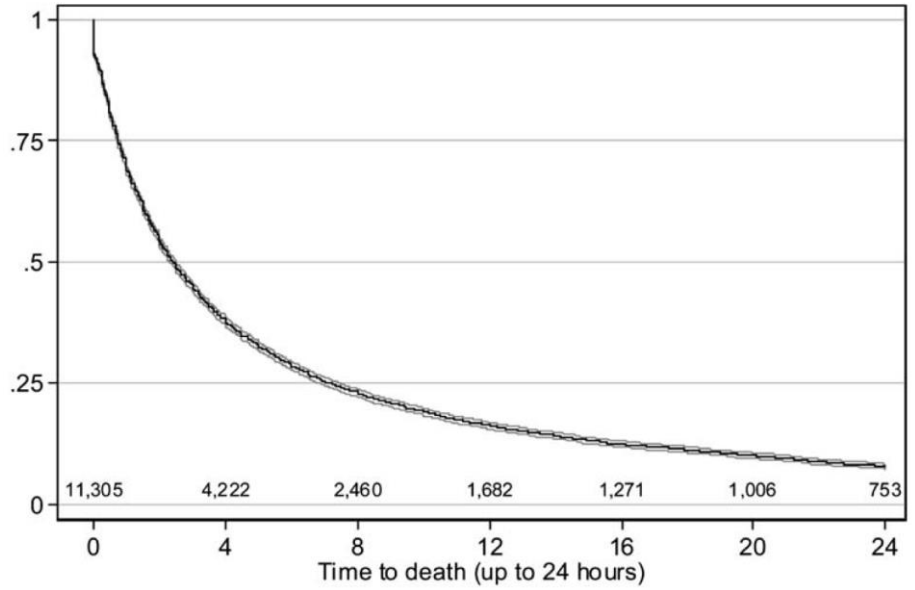
Outcomes

Existing evidence in palliative care in various domains:

- Pain;
- Distress*/delirium/agitation (including existential distres
- Dyspnoea
- Constipation
- Comfort care (thirst/hunger)

Timing

- 2.4 hrs median (Wunsch H et al 2005 ICM 31:823-)
- ICU specialists can predict death within 60 minutes 50% of the time - based on pH, GCS, spontaneous RR,PEEP, and systolic BP. (Brieva et al CCM 2013 41:2677-)



We need to better coordinate this knowledge about timing with good EOL planning

Symptoms experienced by the dying ICU patient

Symptom assessment/ management

Which tools in ICU? RDOS; CPOT; PBAT; BPS; CAM-ICU…

Pain – controversy in practice over moving to S/C from IV

- Short v long-acting opiates v rotating – sub-groups where short-acting might be appropriate? Balancing
- Opioids in managing dyspnoea

Thirst/xerostomia – Care bundles: oral swab wipes, sterile ice-cold water sprays, and a lip moisturizer.

Anxiety/Delirium – Anxiolytics/anti-psychotics – which are appropriate in ICU?

Hunger

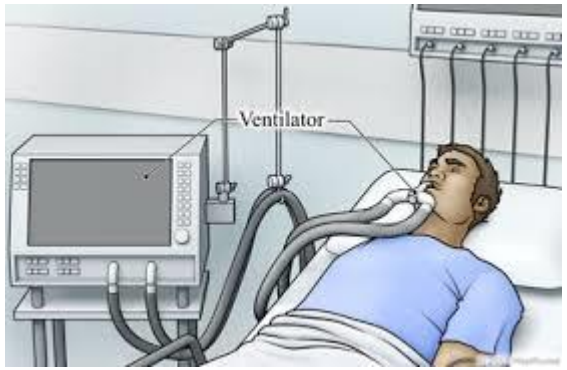
Sleep disturbances

Dyspnoea – Managing air hunger

Process of withdrawal

What we don't have evidence for:

- **One step change** or **2-4+ steps** at **short intervals** (c.10 –20 mins)
- **Reducing FiO²** to 21% (room air) – timing
- **How to reduce pressure support and PEEP**



- **Observational research**: pattern generally - vasoactive medication cessation then withdrawal of ventilation
- **Individualised approach** recommended in worldwide consensus (Paruk et al 2014 J Crit Care 29:902-) and in research (Rajamani et al 2015 Anaesth Int Care 43:335-)
- **Vasoactive drugs** (process)
- **Palliative NIV** (controversy)

Cultural sensitivity; Structural inequalities

- Large scale survey in Canada (n=1543) showed that satisfaction with quality-of-care at the end of life was higher among patients dying in ICU
- But lower among Muslim patients
- Communication barriers between families and healthcare providers also led to lower satisfaction (Nayfeh et al. 2021 BMC Palliat Care 20:145)
- Culturally sensitive communication needed (Brooks et al 2019 Aus Crit Care 32: 516)
- Structural inequalities, racial disparities noted – black patients less likely to have a comfort order initiated (McGowan et al 2022 CCM 50:1-)

COSMIC-ICU

A three-step support strategy for relatives of patients dying in the intensive care unit: a cluster randomised trial

Nancy Kentish-Barnes, Sylvie Chevret, Sandrine Valade, Samir Jaber, Lionel Kerhuel, Olivier Guisset, Maëlle Martin, Amélie Mazaud, Laurent Papazian, Laurent Argaud, Alexandre Demoule, David Schnell, Eddy Lebas, Frédéric Ethuin, Emmanuelle Hammad, Sybille Merceron, Juliette Audibert, Clarisse Blayau, Pierre-Yves Delannoy, Alexandre Lautrette, Olivier Lesieur, Anne Renault, Danielle Reuter, Nicolas Terzi, Bénédicte Philippon-Jouve, Maud Fiancette, Michel Ramakers, Jean-Philippe Rigaud, Virginie Souppart, Karim Asehnoune, Benoît Champigneulle, Dany Goldgran-Toledano, Jean-Louis Dubost, Pierre-Edouard Bollaert, Renaud Chouquer, Frédéric Pochard, Alain Cariou, Elie Azoulay

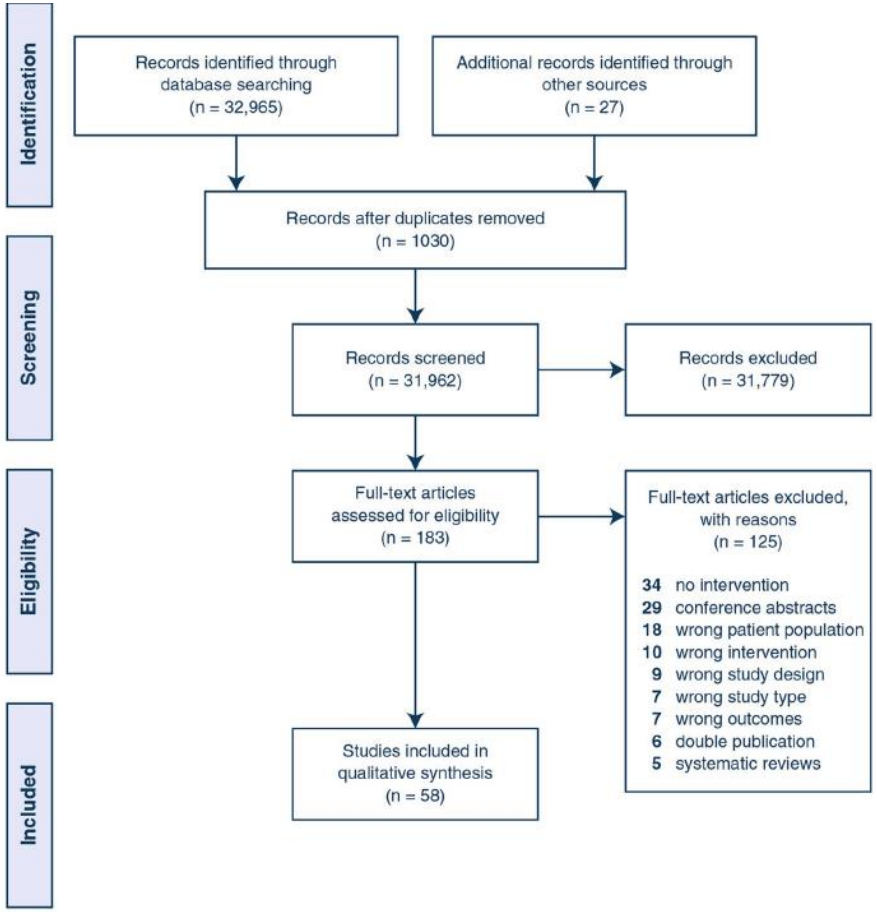
Family conference

ICU Room visit: active support

Family meeting

Kentish-Barnes, N et al 2022. The Lancet 399:10325

Interventions for palliative and end-of-life care in critical care



Summary of Interventions According to the Robert Wood Johnson Foundation ICU End-of-Life Domains

Domain	*n* (%)
Patient-/family-centred decision-making	28 (48.3)
Emotional and practical support (family/patient)	4 (6.9)
Communication within the team and with patients and families	19 (32.8)
Continuity of care	0 (0)
Symptom management and comfort care	6 (10.3)
Spiritual support	0 (0)
Emotional and organizational support for ICU clinicians	17 (29.3)

The total % is more than 100%, as some studies included more than 1 intervention

ICU intensive care unit

Metaxa et (2021) Palliative care interventions in ICU patients Intensive Care Med 47:1415-1425

Interventions for palliative and end-of-life care in critical care

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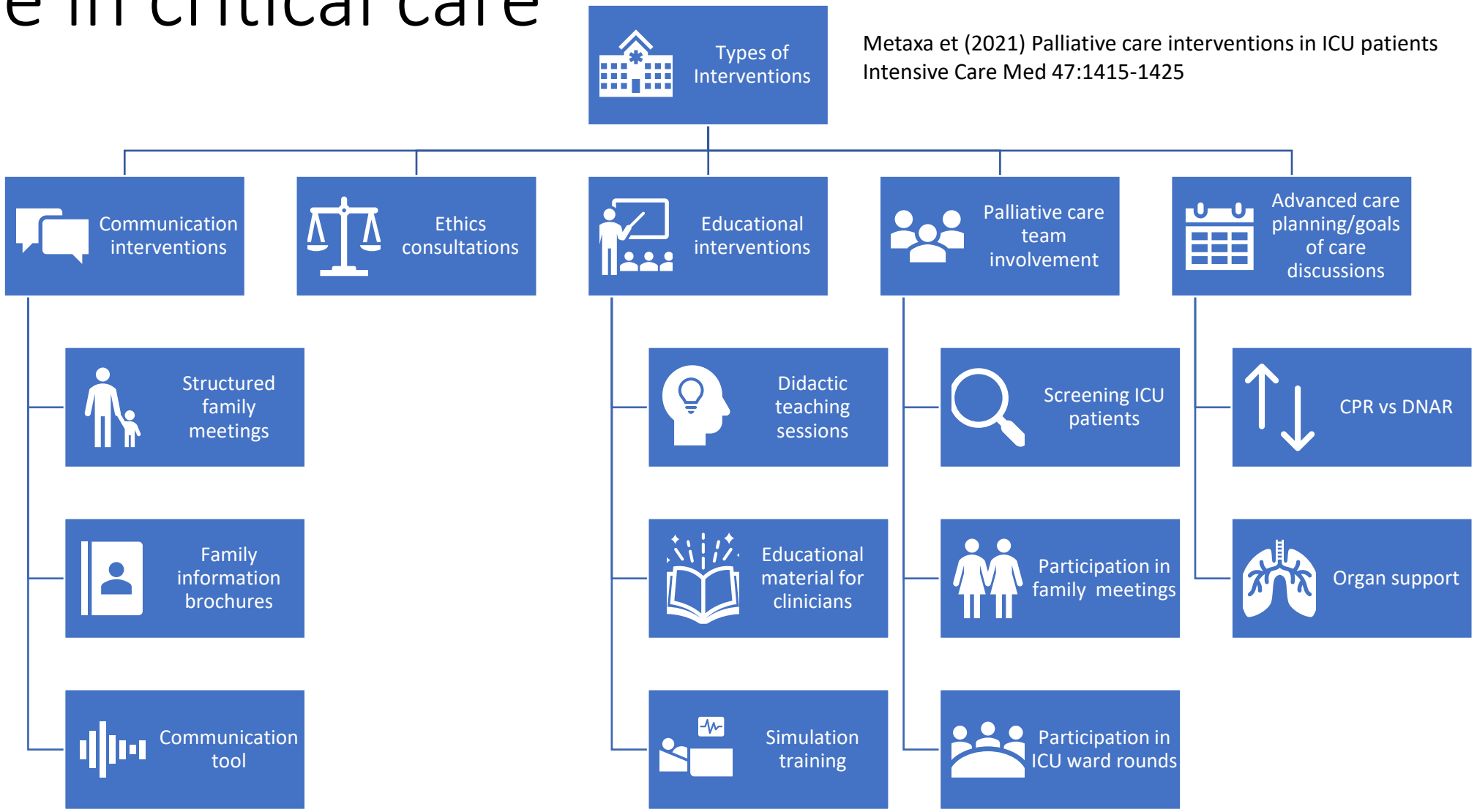

Bereavement

Bereavement and death trajectories

1. **Rapid unexpected death**, where patients are unexpectedly deteriorating (and where EOLD are unlikely to have been made, nor EoL care plans initiated).

2. **Rapid expected death**, where the patient's condition deteriorates, and their death follows a clear decline in the patient's condition. This decline is often related to an acute episode related to a pre-existing chronic illness.

3. **Chronic unexpected death**, where people often have a period of protracted illness leading to an ICU admission.

4. **Chronic expected death**, where it is recognised that the patient is dying and this is likely to occur in critical care.

(Pattison et al 2020 JICS Epub: doi.org/10.1177/1751143720928898)

Bereavement Interventions

- Contacts and opportunity for answers/Signposting
- Condolence letters – worsened family depression at 3m (Kentish Barnes et al 2017 ICM 43: 473–)
- Staff education
- Diaries (+/-) (Galazzi et al 2021 ICCN epub 6.8.21)54444. Pattison et al 2015, Pattison & O'Gara 2014

- QI projects in Edinburgh/Herts
- Pre-emptive care and family support during withdrawal (Pattison et al 2013, J Clin N. 22:1442-)

- Memory-making and mementoes (Riegel et al 2019 Aust Crit Care 32: 442–)

The state of bereavement support in adult intensive care: A systematic review and narrative synthesis

Nikolaos Efstathiou [a,*], Wendy Walker [b], Alison Metcalfe [c], Brandi Vanderspank-Wright [d]

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[b] University of Wolverhampton, Faculty of Education, Health and Wellbeing, Institute of Health, Stafford Street, Wolverhampton WV1 1ND, United Kingdom
[c] Sheffield Hallam University, Faculty of Health and Wellbeing, Robert Winston Building, Broomhall Road, Collegiate Campus, Sheffield S10 2BP, United Kingdom
[d] University of Ottawa, Faculty of Health Sciences, School of Nursing, 3245B Roger Guindon Hall, 451 Smyth Road, Ottawa, ON K1H 8M5, Canada

- A personal memento
- A handwritten condolence letter
- A post-death meeting
- Storytelling
- Research participation
- ICU diary.

Efstathiou et al Journal of Critical Care 50 (2019) 177–187

Risk of complicated grief post-ICU bereavement

- Being of older age
- Refusing treatment
- Feeling prepared for death

- Unsatisfactory physician communication
- Use of emotional support
- Died whilst intubated
- Spouse partner
- Being alone
- Female
- Self blame/Denial
- Being present at death
- Opportunity to say goodbye

Sanderson et al 2022 Plos One 10/3/22

Implementation

Bridging the historic gap between research and practice

Barriers and facilitators have been reported

Factors influencing the integration of a palliative approach in intensive care units: a systematic mixed-methods review

Hanan Hamdan Alshehri[1,2], Sepideh Olausson[1], Joakim Öhlén[3,4] and Axel Wolf[1,5*]

24 studies, 10 countries

Organisational factors (e.g resource and time constraints)

Individual factors (e.g HCP, patient, and family attitudes, communication, skillset and knowledge)

Hamdan Alshehri, H et al 2020. BMC Palliat Care 19: 113

Barriers and facilitators have been reported

Barriers and facilitators in the provision of palliative care in adult intensive care units: a scoping review

Christantie Effendy[1], Yodang Yodang[2], Sarah Amalia[3], Erna Rochmawati[3]

14 studies, 9 countries

Barriers - lack of skillset, family boundaries, cultural differences, and practical issues

Facilitating factors - family acceptance, collaboration, adequate communication, and experience in providing palliative care

Effendy, C et al 2022. Acute Crit Care 37(4): 516-526

PROTOCOL Open Access

Implementation lessons learnt when trialling palliative care interventions in the intensive care unit: relationships between determinants, implementation strategies, and models of delivery—a systematic review protocol

S. A. Meddick-Dyson[1*], J. W. Boland[1], M. Pearson[1], S. Greenley[2], R. Gambe[1], J. R. Budding[3] and F. E. M. Murtagh[1,3]

Looking to the future

What is needed?

- Need more evidence on **decision-aids** and **SDM-** risk/benefit balance models
- **Structured discussions** at point of deterioration
- **Family meetings** most useful in terms of healthcare utilisation
- Research needed to assess if **Advanced Care Planning** (ACP) reduces conflict, and how ACP is applied
- Weak evidence for **education/communication-focused** (written/media)
- Multi-modal training with **patient-level outcomes** and impact needed
- Tools to help ICUs **implement** evidence-based interventions within their own context

Research Challenges

- Ethical sensitivities
- Research with unconscious patients who lack capacity
- Family as proxy measure – often inaccurate

- Subjective measures difficult in this context
- Lack of equipoise
- Emotive and entrenched practices
- Influence of personality/approach; complex interventions required

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