Palliative Care in the Acute Setting:
These three things.....

Dr Anthony Byrne
Cardiff and Vale University Health Board
Marie Curie Research Centre, Cardiff University
Anthony.Byrne2@wales.nhs.uk
@MCRCCCardiff
• One third of all healthcare costs are in the last year of life
• UK: 15 million with long term conditions: 18 million by 2025 with 6 million having two or more
• Three quarters of deaths are expected
Palliative care: evidence

Kavalieratos D et al
Multiple conditions
43 trials  12,731 pts
• Improved QoL: SMD 0.46 (95% C.I. 0.08 to 0.83)
• ↓ symptom burden: SMD -0.66 (95% C.I. -1.25 to -0.07)

Haun MW et al
Cochrane Database of Systematic Reviews 2017,
Issue 6. Art No.: CD011129.
Cancer: 7 trials  1,614 pts
• Improved QoL: SMD 0.27 (95% C.I. 0.15 to 0.38)
• ↓ symptom burden: SMD -0.66 (95% C.I. -1.25 to -0.07)

Quinn K et al
JAMA 2020; 324(14):1439-1450
Non-Cancer
28 trials  13,644 pts
• Less hospitalization O.R. 0.8 (95% C.I. 0.65 to 0.99)
• More ACP O.R. 2.95 (95% C.I. 1.52 to 5.73)
Association between palliative care initiation and healthcare use: Canadian cohort study

Reproduced from Kieran L Quinn et al. BMJ 2020;370:bmj.m2257
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Unscheduled care use in last year of life: Wales
Unscheduled care use in last year of life: Wales
Unscheduled care use in last year of life: Wales
These three things......

• Refractory breathlessness

• Hydration at end of life

• Bereavement – lessons from the impact of COVID
Refractory breathlessness

A focus on pharmacological intervention

• Personal and resource burden

• A bit about mechanisms

• Opioids: evidence to date and key messages
Personal burden

• A multi-dimensional experience with complex interactions

• A highly aversive and fearful state

• In chronic conditions associated with avoidance, progressive deconditioning

• Exertional breathlessness effects 1 in 10 of population
Neural networks and the perception of breathlessness
Exploratory neuroimaging studies:

• Prediction from prior experiences
• Greater ‘top down’ influences
• Amplification of emotion-related brain areas in COPD during anticipation of breathlessness
• Possible increased modulation of emotive responses with chronicity


Opioid receptors

• High density in cortico-limbic area
• Endogenous opioids may modulate breathlessness
• Unclear role for individual opioid receptors
• No clear SNP link
Opioids for breathlessness: effectiveness

- Main evidence base is in COPD
- Significant numbers with heart failure and cancer
- Sequential, updated metanalyses (Jennings 2001, Egstrom 2014, Barnes 2016)

- Most studies have used long acting opioid
- Clinically important difference is 1 point on 0-10 NRS scale
Barnes et al meta-analysis re-analysed

Reproduced from Magnus Ekström et al. Thorax 2018;73:88-90

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New studies:


- Multiple conditions
- S.R. Morphine 20mg daily for 1 week
- No difference for primary or key secondary outcomes
- Slow recruitment – mMRC ≥ 2 included
- Ethics: I.R. morphine available to control group

Reproduced from Currow et al. Thorax 2020;75:50-56

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Effect of Sustained-Release Morphine for Refractory Breathlessness in Chronic Obstructive Pulmonary Disease on Health Status: A Randomized Clinical Trial

• COPD patients: mMRC grades 2-4

• S.R. morphine 20mg-30mg daily for 4 weeks

• Morphine group: improved primary outcome of disease-specific health status: CAT score

• No difference in breathlessness scores

• ‘Worst breathlessness’ improved in mMRC 3-4 group

What’s to come:

**Morphine And BrEathLessness Trial: MABEL**

- Randomized, double-blind, placebo controlled trial
- Multiple conditions; but mMRC grades 3-4 only
- S.R. morphine 10mg – 20mg per 24 hours
- Primary outcome of ‘worst breathlessness’/24 hrs at 4 weeks
- No I.R. opioid in the control group

_Ci: Professor Marie Fallon, University of Edinburgh_
From what we know: Opioid Dosing

• Of those who respond, 70% do so at 10mg morphine per 24 hours

• Almost all who respond do so at 30mg morphine per 24 hours or less

• Maximum benefits often occur several days later

Currow DC et al. J Pain Symptom Manage 2011;42:388-399

From what we know: Safety

• No excess serious treatment emergent adverse events for morphine from recent randomized trials

• Long term cohort study in COPD showed no increased hospitalization or mortality at morphine doses of 30mg or less (Ekstrom et al)

• Morphine-related adverse events (constipation, nausea) have been generally mild

Ekstrom MP et al. BMJ 2014;348:g445
Key messages

• Increasing mechanistic underpinning of role for opioids
• Evidence to date is strongest for sustained release morphine
• Majority of those who respond will do so at dose of ≤ 30mg/day
• Gradual titration warranted
• Excess major adverse events not evident with gradual and proportionate titration
Clinically Assisted Hydration at the end of life
Clinically assisted hydration at the end of life

- Fluid overload
- Respiratory secretions
- Symptom control/wellbeing
- Reduction in EoL delerium
Clinically Assisted Hydration at the end of life

• Good et al Cochrane Review of medically assisted hydration at end of life (2014)
  • 6 studies: 3 RCTs (222 pts) and 3 prospective studies (360 pts)
  • No consistent trends regarding fluid overload or delirium/restlessness
  • Heterogeneity in design and outcomes
  • One study examined survival; no difference between groups

*Good P et al Cochrane Database of Systematic Reviews 2014, Issue 4. Art. No.: CD006273*
Prospective cohort study:

- 371 patients in last days of life categorized by volume intake
- Assessed oral/enteral/parenteral fluid intake
- 40% demonstrated evidence of respiratory secretions – no differences across levels of hydration
- 26% demonstrated evidence of terminal restlessness – no differences between groups
- Hospitalized patients much more likely to have parenteral fluids in dying phase (74%) than hospice (2%)

Cluster randomized feasibility study of CAH at end of life

- 199 patients recruited from 12 clusters in 12 months
- 36.5% entered CAH arm and 38.5% discontinued CAH due to side effects
- No differences in respiratory secretions, delirium between groups
- Large cluster randomized trial feasible

Davies AN et al. Palliative Medicine 2018;32(4): 733–743
CHELsea II: Cluster Randomised Trial of Clinically-Assisted Hydration in patients in the last days of life.

• 1600 pts in 80 clusters across the UK
• Protocolized standard care arm
• CAH administered i.v. or s.c. using weight based volume calculation
• Primary outcome: development of delirium at any point over 14 days of the trial
• Secondary outcomes incl respiratory secretions and survival.
• In set up; due to complete late 2024.

C.I.: Professor Andrew Davies, Trinity College, Dublin
Key messages:

• Inconsistent approach to clinically-assisted hydration at end of life.

• Data suggests greater likelihood of continuation of CAH in hospital setting

• Conflicting results to date on impact of CAH on fluid overload, respiratory secretions, delirium at EoL and survival.

• Current clinical use should be based on individualized goals of care
Bereavement and care in the acute setting – lessons from the COVID pandemic.

Bereavement during COVID-19: A national study of bereaved people’s experiences and the impact on bereavement services

PROJECT INFORMATION

Millions of people across the UK have faced bereavement during the COVID-19 pandemic. The disruption and challenges of this time have impacted people’s experiences of grief, whilst also affecting the bereavement services that support them.

This national study aims to investigate the grief experiences, support needs and use of bereavement support by people bereaved during the pandemic in the UK, and the adaptations, challenges and innovation involved in delivering bereavement support. It is being conducted by a team of researchers at Cardiff University and the University of Bristol, with funding from UKRI via the Economic and Social Research Council.

www.covidbereavement.com
Pragmatic research: routes to impact

- BeCovid Study: lessons for clinical care
- Engagement with policy and strategy frames good questions
- Capacity building – young career researcher
- Impact at pace – lessons learned
Routes to impact:

- **COS**
  - Core Outcome Set
  - Marie Curie funded; COS for bereavement research; first CI role

- **Scoping**
  - Wales Commission
  - Recommended findings accepted in full; Framework for Wales completed; forefront in UK

- **Rapid review**
  - Rapid Covid paper
  - SR of bereavement strategies at times of mass death; WCRC and MCRC resource; collab with Bristol

- **Be COVID**
  - UKRI Rapid Covid fund
  - Study of impact of Covid on bereavement experiences
The BeCOVID Study:

UKRI Rapid COVID Funding
Mixed methods study of bereaved people’s experiences and of bereavement services.

Longitudinal design
Longitudinal design to assess impact over time; rapid set up: funded July 2020 and set up by late August 2020

Iterative learning
Rapid report publication; preprints; multiple media.

Multiple routes to impact
Clinical; academic; policy

Co-C.I.s: Dr Emily Harrop, MCRC, Cardiff University
Dr Lucy Selman, University of Bristol
Experiences of care prior to/immediately after death (n=711)

• 22% of respondents said they were ‘never’ involved in decisions about the care of their loved one; 22% said they were ‘always’ involved

• 18% said they were not at all informed about the approaching death; 32% said they were fully informed

• 35% felt not at all supported by healthcare professionals immediately after the death; 28% very or fairly well supported

• 45% were not contacted by the hospital/care provider after the death; 35% were contacted

• 48% were not provided with any information about bereavement support

Note: Between 12 and 20% answered not relevant to these questions e.g because no HCPs involved, not next of kin
Factors associated with different end-of-life experiences

• Deaths in hospital/care home compared with in hospice/at home increased the likelihood of the bereaved person being unable to visit prior to death or say goodbye as they wanted.

• Deaths that occurred in hospice/at home, and deaths that were expected, increased the likelihood of the bereaved person being involved in care decisions and feeling well supported by healthcare professionals after the death.

• Bereavement due to COVID-19, compared with all other types of deaths, decreased the likelihood of being involved in care decisions and of feeling well supported by HCPs after the death, while increasing the likelihood of being unable to say goodbye.
Increased levels of perceived support from health professionals led to significantly ($P < 0.001$) lower levels of grief measured by Index of Overall Vulnerability (IoV), using the Adult Attitude to Grief Scale, and emotional and overall support need (small to medium effect, $P < 0.001$). This is also seen in the mixed model, where a distinct and highly significant ($P < 0.001$) decrease in IoV is seen with increasing levels of healthcare professional support immediately after the death.

### Please tell us how much help or support you have needed over last 3 months?

<table>
<thead>
<tr>
<th>Support Needed</th>
<th>High or fairly high level of support needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dealing with my feelings about the way my loved one died</td>
<td>60%</td>
</tr>
<tr>
<td>Expressing my feelings and feeling understood by others</td>
<td>53%</td>
</tr>
<tr>
<td>Feelings of anxiety and depression</td>
<td>53%</td>
</tr>
<tr>
<td>Feeling comforted and reassured</td>
<td>52%</td>
</tr>
<tr>
<td>Loneliness and social isolation</td>
<td>52%</td>
</tr>
<tr>
<td>Dealing with my feelings about being without my loved one</td>
<td>50%</td>
</tr>
</tbody>
</table>
Qualitative themes - communication & compassion

Negative
• Difficulty getting information
• Misinformation: patient and policies
• Perceived insensitivity
• Lack of involvement in decisions
• Lack of support/info for home deaths

Positive
• Doing their best
• Compassion and kindness
• Able to visit/spend time with loved one
• Well-informed about patient condition/care
• Hospice and specialist palliative care

(Wife) was admitted there as an emergency and I had to chase for updates all the time. No fewer than ten people promised updates and to get back to me but I received not one call-back. (Bereaved husband)

The two nurses & one of the consultants I had communication with were so empathetic & took their time to explain things & support me in anyway they could during those 5 days. I was aware of how stressed & tired they were but they had a lot of time for me & I’ll never forget that. (Bereaved daughter)
Key messages:

• In hospital experiences can significantly impact on early bereavement experience. Prioritizing in-person visits is warranted.

• Perceived support from healthcare professionals prior to and after death may have a significant impact on bereavement experience and ability to manage grief.

• Healthcare providers need to improve family support after a death, including routinely providing opportunities to discuss patient care and the circumstances of the death, and information about locally and nationally available bereavement support.
GUIDANCE
National framework for the delivery of bereavement care
This framework supports those commissioning or providing bereavement services. This is to ensure that good quality services are available for those who need them.

First published: 26 October 2021
Last updated: 28 October 2021

Bereavement is everyone’s business

The UK Commission on Bereavement

2022 SUMMARY REPORT