

Aim To investigate European Society of Cardiology (ESC) Guidelines' 'typical' and 'less typical', and 'non-ESC' symptoms associated with heart failure, and ESC typical and less typical symptoms regarding setting, age, and sex.

Methods A mixed-method systematic review and narrative synthesis. Systematic search was carried out in six electronic databases. Quality was assessed using Joanna Briggs Institute (JBI) critical appraisal checklists. Symptoms were grouped into typical and less typical, and non-guidelines symptoms. Differences in typical and less typical symptoms were investigated in hospital versus community settings, <65 versus ≥65 years old age, and men versus women.

Results 37 papers (26 quantitative, 8 qualitative and 3 mixed-method research) were included. 62% of participants were male. Mean age was 66 (48–82). Participants in 36 studies reported at least one of 6 typical, whereas less typical (n=10) and non-Guidelines n=37) symptoms were observed in 35 and 37 studies, respectively. Most observed symptoms of each group were: Breathlessness (typical-78%, n=3659); cough (less typical-48%, n=3450); and lack of energy (non-ESC-69%, n=1758). Less typical symptoms (cough, wheezing, palpitation, and dizziness) were different between hospital and community-dwelling cohorts. Typical symptoms (orthopnoea, paroxysmal nocturnal dyspnoea, and swelling) were higher in cohorts ≥65 years old age. Due to the paucity of women's perspectives in studies, there was little information available to compare the symptom experiences of men and women.

Conclusion A comprehensive individual symptom assessment will be required to provide more focused and person-centred care. Thus, clinical management guidelines should include the full spectrum of symptoms in different phases of heart failure (especially, palliative and end of life care).

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CO-PRODUCTION AND PILOT TESTING A WEB-BASED DECISION AID TO SUPPORT PEOPLE WITH MOTOR NEURONE DISEASE CONSIDERING A GASTROSTOMY TUBE (DIAMOND STUDY)

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Introduction A gastrostomy tube (GT) may be offered to people living with motor neurone disease (plwMND) to administer food, fluids and medication when eating and drinking become difficult. However, the evidence base for GT benefit is lacking. Patient decision aids (DA) support shared decision making by providing evidence-based information, elucidating personal preferences and checking understanding.¹

Methods The three-phased DiAMoND study aimed to co-produce and pilot test a web-based DA to support people with MND deciding whether to have a GT. Participants included plwMND, carers and healthcare professionals (HCPs). In Phase 1, the content and design of the DA was informed by semi-structured interviews, literature reviews and prioritisation survey. In Phase 2, the prototype DA was tested with users and developed iteratively with feedback from surveys and 'think-

aloud' interviews. In Phase 3 the DA was evaluated using validated questionnaires.^{2–5}

Results In total, 16 plwMND, 16 carers and 25 HCPs took part in Phases 1 and 2. Interviews and the literature review generated a prioritisation survey with 82 content items. Seventy-seven percent (63/82) of the content of the DA was retained. A prototype DA, which conforms to international DA standards¹, was produced and improved during Phase 2. In Phase 3, 17 plwMND completed questionnaires after using the DA. Most plwMND (94%) found the DA completely acceptable and would recommend it to others in their position, had no decisional conflict (88%), and were well prepared (82%) and satisfied with their decision making (100%).

Conclusion

Gastrostomy Tube Is it for me? was co-produced with stakeholders and found to be acceptable, practical and useful to plwMND. It is freely available from the MND Association website. The DA is a valuable tool to support plwMND and HCPs through the GT shared decision making process.

REFERENCES

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Poster Presentations

Poster Nos 1–4: Bereavement

1

MEDICAL EXAMINERS AND ATTENDING PRACTITIONERS COLLABORATE TO IMPROVE OVERALL END-OF-LIFE CARE AND SUPPORT FOR BEREAVED PERSONS: A SNAPSHOT OF THE MARGARET CENTRE EXPERIENCE

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Background In 2021/22, 1 in 4 of all Whipps Cross hospital deaths occurred on the Margaret Centre (MC), an 11-bedded specialist palliative care unit in London. The centre provides specialist services to Waltham Forest and its environs, through healthy collaborations at various levels. Medical examiners (MEs) routinely support qualifying attending practitioners (QAPs), to improve the quality and accuracy of the medical cause of death certification. In addition, MEs engage with the bereaved, to ensure greater safeguards for the public.

Aim To showcase ME-QAP relationship on a specialist palliative care inpatient unit.

Method Mixed-method approach, comprising retrospective extrapolation of all deaths from 1st April to 31st May 2022, and qualitative analysis of relevant data (convenience sampling).

Results 2021/22 ME vs. QAP cohort:

MEs	QAPs
3 males, 2 females	1 males, 4 females
3 General Practitioners	1 Trust Palliative Medicine consultant
1 Gastroenterology consultant	1 Clinical Fellow
1 Emergency Department consultant	1 Senior House Officer
1 retired Practitioner	1 GP trainee
1 Full-time ME Officer	1 Foundation doctors
Week-day, 1 PA	Week-day, 9am -5pm

Total expected deaths = 54; scrutinised by MEs (85%).

All deaths on MC:

Age 43–100y

Males 22 (41%)

Length of stay on MEs: 0–22days

Reason for admission End-of-life Care 43

Symptom control 10

Outlier 1

Scrutinised in retrospect and real-time (46)

Monday – 22%; Tuesday – 46%; Wednesday – 9%; Thursday – 17%; Friday – 6%

Not-scrutinised (8) Weekend (62%)

[Other reasons: Outlier (25%); Family pressures (25%);

Direct coronial referral (12%)]

Coronial decisions (6)

Port-mortem (50%), Advice (33%), Inquest (17%)

MC QAP response to scrutiny of ‘expected deaths’

‘Is it necessary’

‘Sometimes laborious’

‘A valuable process’ – after witnessing the first successful body donation to LAO

‘On-call service is desirable’

Conclusion Pre-emptive and preparatory scrutiny of deaths is valued by all, and appears to have reduced complaints somewhat. Research is required to evaluate Trust-wide acceptability of the practice.

2 NARRATIVES OF COVID: LOSS, DYING, DEATH AND GRIEF DURING COVID-19

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Introduction The COVID-19 pandemic has impacted people’s personal and professional lives, with many people experiencing various forms of loss including bereavement. The Open University (OU) is a large organisation with many students and staff impacted by the pandemic. The Open Thanatology group at the university noted a gap within the institution to collectively understand and support each other during this time. We sought to provide a space within the OU where students, staff and alumni could share stories and experiences of loss during the first year of the pandemic through narrative writing.

Methods People were invited to submit a narrative of up to 1,500 words to the editors by early March 2021. The editors worked with authors to refine each contribution and self-published the collection in September 2021.

Results Over 30 authors contributed with a range of materials from personal essays, reflections on frontline work or

research, and poetry. Topics included: loss during COVID-19; impossible choices and restricted presence during COVID-19; death and dying during the pandemic; death as a result of COVID-19; grief, loss and funerals during COVID-19; other experiences of grief during COVID-19. Contributors commented that the process was therapeutic and that it recognised and honoured their experiences. For some it was their first-time publishing. It captures a ‘moment in time’ and the difficulties people faced.

Conclusion Publishing the Narratives of Covid book has been a useful way of bringing people together within the Open University and connecting with and sharing people’s experiences of death, loss and grief during the pandemic. Subsequent events at libraries have broadened the conversations beyond the university. Since the book is available as a free download, it has been used in education, research, reading groups, and public engagement.

Book reference Borgstrom, E. and Mallon, S. (2021) Narratives of Covid: Loss, Dying, Death and Grief During Covid-19. The Open University. <https://oro.open.ac.uk/79260/>

3 COMMUNICATION AND DOCUMENTATION AFTER DEATH: INTRODUCTION OF MEDICAL EXAMINER

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Background St Oswald’s Hospice strives to ensure high standards of communication and documentation after death, in line with Hospice UK’s Care after Death guidance, to support bereaved relatives, meet legal requirements and for coronial processes. From April 2023 it will be statutory law that all non-coronial deaths must be reviewed by a medical examiner (ME). The ME role was integrated into our practice from September 2022. This audit aimed to assess our communication and documentation prior to ME introduction and as the role was established.

Methods 100 patients who died in the inpatient unit prior to ME and 19 patients after initial introduction of ME role had documentation reviewed with a standard of 100% in recording:

- Cause of death as stated on the Medical Certificate of Cause of Death (MCCD) and discussion with family
- Whether the patient was for burial or cremation
- External health professionals notified of the death
- Details of any discussion with the Coroner’s office or ME and subsequent explanation to the family

Results (Pre ME and post ME/amending documentation):

- o Cause of death as stated on the MCCD was recorded in medical notes in 97% and 100% respectively.
- o Burial or cremation was documented in 84% and 89%.
- o 100% of GPs were notified of patients’ deaths.
- o Prior to ME 25% of deaths were discussed with Coroner of which 40% had details documented. Post ME 37% of deaths were discussed with Coroner and 63% with ME, 53% of those had details of discussion with family documented overall.

o Documentation of discussions with family regarding content of MCCD was present in 15% and 53% respectively.

Conclusion Introduction of ME and amending documentation templates following initial audit has led to an improvement in communication and documentation after death. Further improvement and re-audit continues.