Results Of the 1428 stories published on ‘Care Opinion’ from March 2019 to 2021 regarding hospitals in the West of Scotland, 48 (3.36%) were related to end-of-life care. We found that people tended to post positive feedback about their experiences with end-of-life care. People reported positively about staff professionalism in providing compassionate and person-centered care to meet their loved ones needs at end of life. Nevertheless, other experiences of care related to challenges facing healthcare services, particularly during the COVID-19 pandemic. Quality appraisal of staff responses highlighted areas for improving feedback. Despite research suggesting conversational responses are more desirable by service users, they were the least popular type of responses in our sample and were mostly from negative stories. In contrast, appreciative responses were commonly from families reporting positively about their experiences of end-of-life care.

Conclusion This study has provided a novel perspective of patients’ experiences of end-of-life care in hospitals in the West of Scotland. Novel insights were importance of trust and meeting patient’s needs at end-of-life particularly by nursing staff.

THE IMPORTANCE OF DECISION-MAKING AT END-OF-LIFE: A SYSTEMATIC REVIEW

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Introduction Caring for the dying is a multidisciplinary team (MDT) model of care, with nurses providing the most direct patient care. Providing end-of-life care to meet the person-centred needs of individuals and families is complex and relies on effective clinical decision-making (CDM) skills. Little is known about how healthcare professionals (HCPs) inform complex decisions for care intervention when the patient is unresponsive at end of life. The cognitive continuum theory (CCT) has been used to examine CDM in healthcare. This systematic review aimed to critically synthesis empirical links between theory, research, and practice to address the following questions: how has the CCT been used in research, and to what extent has it been integrated in research processes and clinical practice?

Methods A systematic review was undertaken searching five databases from inception. A range of key concepts were mapped to each electronic database. Pre-eligibility screening criteria were applied, and methodological quality appraisal was conducted. A meta-aggregate synthesis was conducted using Joanna Briggs methodology.

Findings Five synthesised findings related to the CDM processes were informed by the CCT. These included: CDM varied depending on the decision-making capacity of the individual HCP, their level of experience, availability of decision tools, access to senior staff and peers, and availability of resources such as time and staffing. The visibility of the CCT was variable, with only two studies rigorously applying the CCT to all stages of the research.

Discussion This review identified a gap in providing a person-centric approach to CDM. This finding was dependent on multifactorial considerations which impacted individual HCPs. Complex DM should be safely embedded in the MDT to sustain the team and improve patient care. Further education and support is needed, particularly in the context of the unresponsive dying. Impacts of time, resources and workplace culture on CDM need to be addressed.

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PREDICTING THE FUTURE: WHEN FAMILIES ASK THE ‘HOW LONG ...’ QUESTION AT END-OF-LIFE

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Background Multiple tools exist to aid prognosis at end of life, yet predicting the length of time to death once the person is unresponsive and deemed to be ‘imminently dying’ remains fraught with uncertainty. Knowing approximately how many hours or days their dying loved one has left is crucial for both families and clinicians to guide decision making and planning end-of-life care. Previous research has produced useful indicators, but definitive data on length of time from unresponsiveness to death are not reported in the literature. This research sought to determine the length of time between becoming unresponsive and death.

Method A retrospective clinical audit of electronic records of 786 patients receiving specialist palliative care as inpatients, at home, and in aged care homes was conducted across a 10-month period. We analysed the time from the first Karnofsky score to death and used Kaplan-Meier survival analysis to determine the duration of patient’s final phase of life, taking into account variation across age, sex, diagnosis, and location of death.

Results From the first time the patient was scored as Karnofsky 10, 49% of patients were unresponsive for longer than one day, with a median duration of 2 days. Regardless of age, the probability of not surviving is identical across all age groups on day two. Having adjusted for age, malignancy, gender, and location, the likelihood of death within 4 days is over 75%. The data also reveals that, regardless of diagnosis, there is a tipping point at around 20–30 days prior to death, from where there is a notable decline.

Conclusion This new data will have a major impact on clinician’s confidence when responding to the ‘how long’ question and can be used to inform decision-making at end-of-life. Findings demonstrate that the Karnofsky 10 score is a highly reliable prognostic indicator.
SHOULD HOSPICES PROVIDE INPATIENT CARE TO PATIENTS VOLUNTARILY STopping EATING AND DRINKING WITH INTENT TO HASTEN DEATH? AN ETHical ARGUMENT TO SUPPORT PATIENT AUTONOMY WHILE ACKNOWLEDGING PROFESSIONAL DISCOMFORT

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Background Voluntarily stopping eating and drinking (VSED) with intent to hasten death, even in the context of concurrent disease, can be argued to constitute a form of suicide, albeit by omission rather than act. In the UK, therefore, where assisted suicide is not legally permissible, providing inpatient nursing and medical care to a patient competently withholding food and fluid intake with the aim of ending their life potentially raises legal and ethical challenges.

Argument We argue, however, that healthcare professionals are ethically bound to uphold patient autonomy, and an informed, capacitous decision to voluntarily stop eating and drinking represents autonomous patient choice. Furthermore, to force enteral or parenteral fluids or nutrition on a capacitous patient would constitute battery. Assuming patient capacity is maintained, and the provision of basic care including the offer of food and fluids continues, providing care to patients voluntarily stopping oral intake is legally unproblematic. Ethically it is not necessary for healthcare professionals to share the patient’s intention of hastening their death to provide clinical care, hence they should not be considered complicit or instrumental to a patient’s deterioration through VSED.

Inpatient care may be necessary for patients voluntarily stopping eating and drinking to ensure optimal physical and psychological symptom management towards end of life, with hospices being ideally placed to meet these needs. Declining to admit such patients to a hospice on the basis that this may constitute assisting suicide risks leaving them vulnerable to suboptimal symptom control and merely displaces ethical discomfort onto an alternative group of healthcare professionals.

Conclusion Hospices should be open to providing inpatient care to patients voluntarily stopping eating and drinking, confident in the ethical clarity that they are supporting patient autonomy, but acknowledging the moral burden for involved healthcare professionals who may not share a sentiment to hasten death.

SEDATION OR ASSISTED DYING? AN ETHICAL ARGUMENT

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Introduction Palliative care facing the unbearable, sustained suffering of some terminally ill patients seeks ways to relieve this suffering, while staying within professional ethical boundaries that can change over time. Given that the proposed Assisted Dying for the Terminally Ill Adults (Scotland) Bill is currently going through the Scottish Parliament, it is worth comparing forms of terminal sedation to assisted dying from an ethical perspective.

Argument A procedure that causes less harm while achieving the same benefit is preferable to a treatment that causes greater harm. Certain forms of sedation do not terminate life. Assisted dying terminates life, which can be seen as the ultimate harm.

Both achieve an end to suffering for the patient. Therefore, certain forms of sedation are preferable to assisted dying.

Details Life can be said to have an intrinsic value, and to avoid doing harm is an established ethical principle. Forms of sedation that do not terminate life are late deep continuous sedation, intermittent deep sedation, and proportionate palliative sedation. Only the latter is widely practiced in the UK. Sedation can be said to cause the lesser harm of unconsciousness, compared to the greater harm of death. However, too light sedation is insufficient to relieve suffering whilst too heavy sedation can contribute to the termination of life. To terminate life through assisted dying can be seen as the ultimate violation of the ethical principle to do no harm. Both assisted dying and forms of sedation can be said to relieve subjectively experienced, unbearable suffering.

Conclusion Late deep continuous sedation, intermittent deep sedation, and proportionate palliative sedation respect the intrinsic value of life, thereby avoiding the main ethical objection to assisted dying. It is important to explore, in detail, the role and practicalities of various sedations for palliative patients.