

BMJ Open Quality Improving quality in hospital end-of-life care: honest communication, compassion and empathy

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To cite: Rawlings D, Devery K, Poole N. Improving quality in hospital end-of-life care: honest communication, compassion and empathy. *BMJ Open Quality* 2019;**8**:e000669. doi:10.1136/bmjopen-2019-000669

Received 25 February 2019
Revised 14 May 2019
Accepted 16 May 2019



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ABSTRACT

Background With over half of expected deaths occurring in acute hospitals, and a workforce not trained to care for them, good quality end-of-life care in these settings is hard to achieve. The *National Consensus Statement on Essential Elements for Safe and High-Quality End-of-Life Care* has been translated into e-learning modules by the End of Life Essentials project, and this study aims to demonstrate how clinicians interpret the Consensus Statement in their day-to-day practice by answering the question at the end of each module: ‘Tomorrow, the one thing I can change to more appropriately provide end-of-life care is...’

Methods The modules were developed by a palliative care educator with the support of a peer review group and were piloted with 35 health professionals. Pre-post module evaluation data were collected and during a 10-month period from 2016 to 2017 a total of 5181 individuals registered for the project accessing one or more of the six modules. The data from 3201 free-text responses to the post hoc practice change question have been analysed, and themes generated.

Findings Five themes are derived from the data: communication, emotional insight, professional mindset, person-centred care and professional practice.

Conclusion Learners who have completed End of Life Essentials have shared the ways they state they can change their practice tomorrow which may well be appreciated as a clinical response to the work by the Australian Commission on Safety and Quality in Health Care in leading and coordinating national improvements in quality and safety in healthcare in Australia. While intent cannot guarantee practice change, theory on intention—behaviour relations indicate that intentions have a strong association with behaviour. This indicates that the modules have the ability to influence end-of-life care in acute hospitals.

INTRODUCTION

An estimated 50% of deaths in Australia are expected¹ with approximately 54% occurring in hospital,² with the likelihood of hospitals keeping up in terms of good quality end-of-life care in question.^{3–4} Similar figures are reported elsewhere,^{5–8} indicating that this is not just restricted to Australia.⁹ The numbers of deaths are projected to increase¹⁰ in conjunction with a system-level default to

continue lifesaving treatments, living well towards the end of life in acute hospitals is a challenge.¹¹ Healthcare professionals (HCP) who work in acute hospital settings are often highly trained and skilled in rapidly diagnosing and responding to patients with deteriorating health but usually with a focus on cure.¹² There is often limited capacity of these HCPs to recognise dying, with poor communication common, and invasive clinical investigations the norm.¹³ Arguably though, treatment of symptoms and response to those with a life-limiting illness requires a different set of skills.

In 2015, the *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care* (the Consensus Statement) was released by the Australian Commission on Safety and Quality in Health Care (ACSQHC) who leads and coordinates national improvements in this arena. The Consensus Statement contains recommendations for clinical practice in end-of-life care in hospitals, endorsed by the National Health Ministers as the national approach to the delivery of quality end-of-life care.¹ While it is a fundamental step towards improved care, providing a blueprint for HCP and the healthcare sector, it does not provide practical steps or translational directions.⁸ Such direction should include how to develop skills and gain confidence in recognising when patients are approaching the end of life, as well as communicating with and managing the care of patients at the end of life, and their families.

The first five elements of the Consensus Statement (box 1) provided the basis for a major national education project (funded by the Commonwealth Department of Health) End of Life Essentials (EOLE). The project, conceptualised and developed at Flinders University South Australia, in effect, operationalises the essential elements identified in the Consensus Statement and builds on the work already identified. EOLE provides free evidence-based, peer-reviewed online

Box 1 The Consensus Statement—processes of care elements

- ▶ Patient-centred care.
- ▶ Teamwork.
- ▶ Goals of care.
- ▶ Using triggers.
- ▶ Responding to concern.

learning modules to help build the capacity of HCPs in Australian hospitals.¹⁴ The modules are designed for doctors, nurses and allied health professionals (AHP) working in acute care settings and cover: dying (a normal part of life), patient-centred communication and shared decision-making; recognising end of life; goals of care; teamwork; and responding to concerns. The modules are case based with evidence-based resources and web pages available to support learning and were released in two stages: modules 1–3 in June 2016 and modules 4–6 in October 2016.

To inform future module development it was important to know what learners do with their new knowledge and what they plan for changes in practice. At the end of each module, a question is posed: ‘Tomorrow, the one thing I can change to more appropriately provide end-of-life care is...’ This statement changes slightly to make it relevant to each module, allowing the learner to consider what they have learnt and how practice can change immediately. It also allows the researchers to understand the impact of learning and the scope for practice change. The responses from this activity are the focus of this paper, highlighting how the Consensus Statement, as a guide to improve quality and safety and the education derived from it, can influence change in attitudes, behaviour and practice, which in turn impacts end-of-life care and the patient experience.

METHODS

Developing the education modules

From inception, quality, consultation and industry partnership were paramount. A National Advisory Group (NAG) included the project coleads, ACSQHC delegates and key stakeholders representing health professionals. The modules were developed by a palliative care educator with the support of a peer review group (invited by the NAG) and were multidisciplinary hospital clinicians from across Australia. Following this, 35 doctors, nurses and AHPs piloted the modules. In order to elicit the changes to their own practice that acute hospital HCPs recognise from education derived from the ACSQHC Consensus Guidelines, a question was incorporated into routine evaluation, where learners voluntarily answered, in free text, the following question: *Tomorrow, the one thing I can change to more appropriately provide end-of-life care is...*

Patient and public involvement

Patients or families were not included in this process, having been involved in development of the Consensus Statement from which the education is derived.

Data collection and analysis

Data have been included from any health professional (self-selected) who completed one or more of the six modules from 1 November 2016 (following the final module release) to 28 September 2017 (the date of the data extraction). A total of 5181 individuals registered for the project during the time period. Data were extracted and deidentified by an administration officer. Data were analysed and a coding scheme was developed independently by a research assistant with no prior knowledge of module content. This was reviewed by the broader team who consolidated the coding scheme and examined emerging patterns. Internal homogeneity and external heterogeneity were established by verifying the meaningfulness and accuracy of the placement of data in the various codes.¹⁵ Analytical categories were derived inductively from the data, and the data were read and read again to recognise and code themes and subthemes.¹⁶ NVivo V.11 was used to assist with the sorting, organisation, reorganisation and storage of data, and thematic analysis informed our data analysis.¹⁷ Themes were systematically and coherently compared to identify as many nuances as possible.¹⁸

RESULTS

The themes from 3200 responses were organised in five broad categories concerning intent-to-change practice: *communication*, *emotional insight*, *professional mindset*, *person-centred care* and *professional practice*.

Communication

This theme included a variety of ways respondents intended to change their clinical communication. Many detailed that they would aim to be more open to questions from patients, families or even their teams—effectively wanting to change their willingness to broach, and respond to, end-of-life issues. A subtheme *curbing own avoidance* to end-of-life issues in conversations with patients was stated as key to providing appropriate care, even being able to say the word ‘dying’ in conversations was reported as more appropriate. The subtheme of *end-of-life discussions* holds statements of respondents who aimed at being open, honest and providing full information and advocating on behalf of patients and families as steps that could normalise dying in hospitals. *Listening effectively* was another subtheme where respondents acknowledged that listening is a powerful part of communication and end-of-life care—hearing and listening to *what the patient wants and wishes* is key. However, it was identified that such willingness and open communication also posed potential associated risks. While stressing the importance and positive impact (for patients’ care and families’ bereavement) of being able to communicate end-of-life issues,

respondents also described the perceived side effects of the emotional nature and labour of such communications. Discussing dying and death in hospitals is essential but can trigger emotional responses in staff and conflict in clinical teams or even with families. Respondents stated clearly that these risks can be mitigated by being prepared, skilled and equipped for conflict and high emotion. *Non-verbal communication*, another subtheme, captures techniques that could improve practice. Sitting, appropriate touch, a smile or even an attentive look or body posture were mentioned as areas where they could change practice and strengthen end-of-life care.

Virtues and emotional insight

Virtues and emotional insight were a theme used to group and capture the respondents' considerable descriptions of thoughts, feelings, empathic approaches and moral awareness. This included intent to alter or heighten self-awareness and reflect on thoughts and feelings while thoughtfully responding to families, patients, friends and staff on end-of-life issues. *Awareness of own emotions* was another subtheme capturing capabilities of being reflective and thoughtful about what could be said, and the impact of words included in conversations. Also, being extra *aware of others' emotional state*, another subtheme, was an additional implementation skill. Respondents mentioned *being brave*—as listening to and being aware of another person's sorrow, anxiety and '*being there*' in the face of their suffering requires a strength in or braveness of professional character.

Compassion is a subtheme that included responses regarding the ability to be open to the suffering of others in the face of one's own fear while providing care to alleviate suffering. Also mentioned was 'not avoiding' discussion on dying, showing compassion by answering questions honestly and objectively. In order to relieve suffering, the respondent told us they could be brave and compassionate in their '*feelings, skills, thoughts and words.*'

Another subtheme was *being aware of the concerns, fears, emotions and feelings of the patient*. The business of providing care and service in a hectic acute care hospital can mean that conversations and identification of needs can be kept at a 'surface' level. However, the respondents stated that a commitment to a deeper level of understanding of the dying patient's needs, fears and feelings could be translated to their practice to improve the quality and safety of their practice. Not being afraid, as practitioners or clinicians, to use the words 'dying' or 'death' in conversations, acknowledging patient's concerns and being in tune with the patient with a heightened sense of mortality were all translatable capacities that were stated by respondents. Increasing one's *empathy*, another subtheme, was specifically mentioned by respondents as an area of practice improvement. Being able to embrace the patient's experience or walking in other person's footsteps was important. Such a heightened awareness can raise challenges even for the most experienced clinicians and this was captured in the subtheme *controlling my own emotions*. Translatable

skills and the capacity to 'step back' reflect and attending to self-care and one's own emotional state were offered by respondents as strengthening practice change points.

Dignity, valuing and respecting the patient for his or her own sake, was another subtheme where respondents specified they could change their practice. Being able to honour the personhood of the individual patient and their specific needs was a dignified approach to end-of-life care that could strengthen in professional practice. While no respondent admitted to being dishonest, *honesty* was mentioned as an area of practice change. Trying not to avoid using the word 'dying' was yet again mentioned by respondents. Also, respondents stated that answering questions and responding directly was a strengthening practice in quality end-of-life care—questions that arise in clinical end-of-life practice are commonly about the future (*what will happen to me?*), rather than skirting and dodging the question acknowledging it with a respectful and honest response is required.

Professional mindset

This theme included a variety of ways respondents intended to change their professional mindset. A subtheme was *confidence* in professional practice which held descriptions of intentions not to be scared or frightened, to be brave and truthful. The respondents stated that their approach to care could be altered to enhance these virtues which underlay quality end-of-life care. Such virtues that underpin quality care are held together by professional *self-care* and respondents described the importance of self-care, another subtheme. Proactive investment in self and energising practices were descriptors provided by respondents on how they could invest in their own capacity. Another subtheme was *open-mindedness*; respondents specified that they could alter practice by not being judgemental of various cultural and religious beliefs and respecting the viewpoints of others are ways that could improve practice. *Upskilling* was another subtheme developed to capture respondent's descriptions of working towards excellence and developing practice over time. To learn, to develop and to educate others were all included in this subtheme. Also important is to recognise the qualities and capacity already held in clinicians—the respondents wrote it is important to pat yourself on the back while also aiming high for clinical practice improvement.

Person-centred care

This theme included a variety of ways respondents intended to strengthen their capacity to deliver person-centred care. Understanding *the goals, needs and expectations of the patient* was a subtheme where intentions were collected about allowing patients to be heard, to be in tune to the patient's needs and their wishes for the future. Goals of care are for and designed by the patient, not the healthcare teams. Being able to *respect the patient, their family and wishes* is a subtheme that included a variety of ways respondents intended to improve their practice

by empowering and respecting patients' choices. Even if patients' wishes are different from an individual clinician's quality end-of-life care it embraces respect and upholds patient autonomy. Being able to *separate the patient from the illness* was another subtheme based on respondents' replies regarding the ways to acknowledge the person, not the illness or disease, an enabler of person-centred care. *Supporting the patient and the family members* is a subtheme that collected the respondent's descriptions of the various ways support can be offered at the end of life. This included providing symptom control, referral for spiritual or pastoral care, a listening ear and being a mediator when miscommunication happens. *Taking time to be with the patient* was another subtheme based on the respondents' replies, where allowing and giving time was mentioned as an area, they could change to deliver quality end-of-life care. Taking time to listen, to leave 'to-do lists' and just 'be' were mentioned as strengthening along with not offering quick reassurances to end-of-life issues. Allowing time just for silence was also offered as an area to improve appropriate quality of practice.

Professional practice

Professional practice was a theme developed to capture the specialised qualities of practice needed to deliver end-of-life care. *Advocacy of the patient* was a subtheme where respondents wrote the importance of actively supporting the patient in team meetings or other fora where patient's preferences and wishes are being overtaken by bureaucratic or organisational and professional preferences. Advocacy of the patient also included ensuring other HCPs can see the patient's point of view. *Acting quickly* is a subtheme that includes the realisation that end-of-life care can be urgent care, where occurrences of suffering or uncontrolled symptoms means that escalation to other teams in the hospital can alleviate ongoing distress and offer appropriate treatments. Being able to question colleagues or hospital standard operating systems is another area where practice can be altered to improve care, and these subthemes were collected in *asking questions*. Understanding illness trajectories and not missing opportunities to broach and discuss the patients' future care plans is a subtheme called *identify end-of-life triggers*. *Telling the truth with kindness*, as one respondent stated, can happen at opportune times that allows quality patient-centred care at the appropriate time. Respondents also wrote about not missing an opportunity to offer to discuss end-of-life issues with patients and triggers are key to this end.

Including patients and families in the healthcare team is another subtheme where intentions to alter practice for the better were collected. Feeling like you are not alone and recognising and using a team where decisions and goals can be made respectfully have the potential from respondent's perspective to alter practice for the better. Effective *leadership* was a subtheme used to collect the practice change intentions of respondents. Clear goals, clear roles, trust, respect and a cultural readiness to allow

patients to steer care were all mentioned as practice change points that could be instigated.

Qualitative comments by theme are detailed in [table 1](#).

DISCUSSION

Overall, our findings suggest that most respondents thought they could change their practice for the better, nominating what they could do to improve appropriate care. There were no responses or suggestions that practice changes could not be implemented or that nothing could be changed. Respondents were generous with their comments, and optimistic that change could be achieved. *One thing I can change* was interpreted at an individual level as there was no reference to other HCP or the organisation itself had roles in these changes. Findings regarding the professional virtues of compassion, dignity, empathy and honesty underscore how important HCPs see these qualities in delivering end-of-life care.

Definitions of what constitutes quality end-of-life care vary and are subjective.^{3 19} A study of 49 acute care nurses in America²⁰ detailed eight nursing actions to promote dying well: communication with disciplinary team/nursing staff, provision of optimal physical care, demonstration of caring and compassion, supporting dignity in death for patient/family, education of patient/family to support dying well, emotional support for patient/family, advocacy for dying well and fostering a peaceful environment. Conversely, a study conducted in Malaysia²¹ with 553 acute care nurses highlighted the main barrier to quality end-of-life care was the emotional work required in 'dealing with a distraught family,' while focus groups/interviews in acute care hospitals in the UK³ found a main deterrent to good quality care was in delays in diagnosing dying, all of which are reflected in themes or subthemes in our study.

The learners who have completed EOLE have shared the practical ways they state they can change their practice tomorrow (ie, intent to change), which could then be appreciated as a clinical response to the ACSQHC work in this space. EOLE has provided a way for HCPs in hospitals to learn more about the essential elements of end-of-life care ([box 1](#)), handed down by the Consensus Guidelines and expressed and interpreted through a suite of free online learning modules. Themes were subsequently derived from the evaluation data, demonstrating how clinicians have reinterpreted these essential elements and intend to use them in practice ([table 1](#)).

Communication

Communication is reported throughout and has been cited in the literature as a main factor that can influence and help improve end-of-life care in hospitals³ so its importance cannot be underestimated. Aspects of communication were highlighted by respondents; however, having open and honest conversations is something that many HCPs either struggle with²² or are unaware that this is wanted or required. End-of-life communication was

Table 1 Intent-to-change end-of-life care practice as identified by 3200 healthcare professionals, by theme and subtheme

Thematic and subthematic categories	Archetypal quotes
Communication	
Curb my own avoidance	<i>Do not avoid—ask questions openly and respectfully. Use the word dying and communication effectively with not only the patient but their families and the team.</i>
Conflict and conflict management	<i>Goals of care to be negotiated and share plans of health care. Negotiate goals of care with patients as this is an essential skill for all nurses & professionals...conversations about end of life can trigger emotions in us. Goals of care conversations can become emotional, the key is to be prepared stress that conflict, or even difference of opinion, is a reality, having a strategy to manage conflict is essential. Good communication matters to families and can lead to healthier bereavement.</i>
End-of-life discussions	<i>Taking cues from this module, initially respond to a person's concerns by acknowledging their concerns or emotions...an opening into frank, straightforward discussion, rather than saying 'ummm' and not knowing how to respond, or whitewashing or glossing over their concerns. To make sure that the patient has informed information to be able to make their own choices and decisions about the care they feel they would like surrounding their end of life care. This information should also be shared between staff and correctly documented. Goals should be continually discussed with as these Goals can change through the progression of the patient's illness. Recognising when a patient may be at the end of their life and ensuring that conversations and family meetings are had to ensure that the patient is expressing and communicating how they want their treatment to go. That their goals of care are heard and respected.</i>
Listen effectively	<i>To listen, give respect, talk about goals of life and involve the patient and family into the decision of treatment and symptom control. What does the patient want? What's their care plan? Respond to patient's questions/fears by listening, communicating care being provided—with empathy, respect and dignity....</i>
Non-verbal	<i>Pull up a chair. Is the first most important thing we can do with our patients, by listening, touch, or just a smile speaks volumes, I have patients that speak with their eyes, no need for words, this is a very basic human need, to know that someone cares & is there or listening. Listen for queues that can kick start a normally difficult conversation. Take time to listen. Acknowledge the pts feelings. Be truthful and state 'I don't know'. Use the word dying if appropriate....Use body language that provides signals to the patient and family that you are concerned and prepared to listen.</i>
Open communication	<i>Start having open and honest conversations and asking more about patient's future wishes. Even though the Allied health position I am in is not normally the lead of these conversations, I could start talking more about what happens if you don't get any better or what would you like to see happen in the future. Have an open and honest discussion with patients about their end of life plans and hopes. Also be aware of the ICU trajectory and how we can work to normalise death and dying.</i>
Speaking and responding more effectively and appropriately	<i>Acknowledge the concerns of patients and their families. Stop what I am doing (including any planned intervention) and actively listen to the patient's concern. Don't be afraid to use the word death in conversations around end of life care. Provide clear expectations for patient and when this can't be done by my profession, liaise with the treating team regarding the patient's and family's desire to know what is going on...</i>
Use appropriate language	<i>Not fear the words 'die' and 'death' when communicating with unwell patients when they question me.</i>
Virtues and emotional insight	
Awareness of my own emotions	<i>Being more self-aware of my thoughts, feelings and what is coming out of my mouth. To not be nervous about open communication and having meaningful conversations with people about death. To understand the situation, to communicate to family and friends giving a clear picture of the situation, and to communicate the next stage of care for the patient. Checking the understanding of the family members to ensure everyone is clear on the next stage. Taking care of myself in the process is important to ensure I can be reflective throughout my dealings with others who are experiencing strong emotions and difficult time of coming to terms with impending loss. I would make sure that I maintained communication with in the team, the family and the patient. Upskill my own skills and knowledge to handle emotional and conflict issues and also to check my own emotions when dealing with conflict issues and debriefing with team member when needed. Referring to other staff who maybe more equipped to handle situations appropriately because of their skill level...</i>

Continued

Table 1 Continued

Awareness of others' emotions	<p><i>Acknowledge the anxious times that patients are feeling and not avoid the difficult conversation. If I cannot answer the question, find the right person / doctor who can and all team members support and reinforce the same response.</i></p> <p><i>Be more brave—be aware that it is a horrible discussion to have for any family, but I am the person that can start these discussions and help someone through this. It is not about me, it is about the patient and their family and loved ones.</i></p> <p><i>To really listen to what the patient is saying, and ensure communication is open and effective and the patient is never ever aware of time or feels rushed. I would like to ensure that any patient I have contact with is comfortable and feels safe to be able to open up and communicate their needs, wants, fears and not only feels that they have been heard but can see that by my actions...</i></p> <p><i>Don't avoid conversations and communicating serious news—escalation of the patients suffering, the families sorrow and staff distress can happen quite quickly and requires an urgent response. There are many options for managing conflict and responding to concern, whether it is your concern, your teams, the patient or family.</i></p>
Compassion	<p><i>Being more compassionate and using the word 'death' in conversations; so as not to avoid the word 'death' or give patient's false hope on their health.</i></p> <p><i>Encourage open but compassionate discussion with a patient and/or their family about their changing situation; establish their expectations and aim to align them with the goal of care with respect to the patient's condition/prognosis.</i></p> <p><i>Do not assume. Ask appropriate questions, involve all members of the patient's family and friends that they wish to be involved. Allay fears and act in a competent, compassionate manner with skills, feelings, thoughts and words.</i></p>
Aware of the concerns, fears, emotions and feelings of the patient	<p><i>Commit to always listen to what may be behind any veiled question a patient may ask, and encourage him/her to ask what it is they really want to know. It is easier to just keep it all surface when you are busy. Recognise more the impact of the diagnose of a terminal illness on a person, even if at the time he/she is feeling reasonably well. Encourage more discussion. Acknowledge the concerns of patients and their families. Stop what I am doing (including any planned intervention) and actively listen to the patient's concern. Don't be afraid to use the word death in conversations around end of life care. Provide clear expectations for patient and when this can't be done by me, liaise with the treating team regarding the patient's and family's desire to know what is going on. Provide emotional support to patients and their families.</i></p>
Empathy	<p><i>Respond to patient's questions/fears by listening, communicating care being provided—with empathy, respect and dignity. But also asking if they have someone who can speak for them when they are no longer able to speak for themselves; and asking them if they have spoken to that person about what is important to them.</i></p> <p><i>Don't rush. Give them the opportunity to talk stop and listen ask them to express what it is that concerns them the most now ask if they would like to talk about it or their goals of care. Be active listener show respect support and empathy allow the family time to include both patient and family don't miss the opportunity if it presents.</i></p> <p><i>Learn to embrace patient understanding and work on my empathy to improve my understanding of their perspective.</i></p> <p><i>Step back and reflect, seek support, being prepared for difficult situations, active listening, empathy, providing information/education. Up skilling conflict resolution. We are all here for the patient and their family as they face death and dying issues.</i></p>
Dignity	<p><i>Listen to my patient, treat respectfully and with dignity. Don't rush in to 'fix' the issue, it may not be fixable, raise false hopes. Be truthful and be kind.</i></p>
Honesty	<p><i>Listen to patient's concerns/fears and respond honestly within my scope of practice. Advise other staff members who may be able to provide additional support/reassurances.</i></p> <p><i>To not avoid the use of the work 'dying'. It's a part of life and in order to provide patients with all the aspects and knowledge regarding their care and condition, it is important to be honest and address their fears/concerns regarding death.</i></p> <p><i>Do not be afraid to use the 'dying' word in an honest conversation.</i></p> <p><i>To listen more intently to my patients, acknowledge their fear and be honest with them when answering questions. Endeavour not to shy away from the hard questions. When I'm unsure of anything, seek my colleagues input. Respecting everyone's situation and assist in any way I am able to do so.</i></p>
Professional mindset	
Confidence	<p><i>Be brave in my response and answer truthfully.</i></p> <p><i>Continue to be brave and talk about death and dying within the context that it is not something that we as a society necessarily do very well and that it doesn't have to be something to be frightened of talking about.</i></p> <p><i>Being willing to 'go there' with patients if they raise the issue of death, in terms of its inevitability for us all, rather than just directing them to the doctors for more info/ a more informed 'guess' of time (probably do both those things).</i></p>

Continued

Table 1 Continued

Engaging in self-care	<p>To understand the situation, to communicate to family and friends giving a clear picture of the situation, and to communicate the next stage of care for the patient. Check the understanding of the family members to ensure everyone is clear on the next stage. Taking care of myself in the process is important to ensure I can be reflective throughout my dealings with others who are experiencing strong emotions and difficult time of coming to terms with impending loss.</p> <p>As a health care provider know your strength and weaknesses, do not be ashamed to ask for support if required.</p>
Open-mindedness	<p>Listen and be more open to see others viewpoint without being judgmental.</p> <p>Ensure that the patient and his family, or the people of his choice are included in all of the 'meetings'. Any treatment or lack of treatment, needs to be discussed and explained to the patient and his family. We are a team. ...For many people there is a spiritual belief and this is more important than any other care.</p>
Upskilling	<p>Work towards being 'able' to have the conversations rather than being a 'novice'. Adapt and adopt phrases that will help me address the conversations.</p> <p>...continue educating myself about end-of-life care, being thoughtful in my practice and giving myself credit for already being a good clinician.</p>
Person-centred care	
Goals, needs and expectations of the patient	<p>Treat dying as an ongoing process and don't be afraid to use the "d" word". I love the phrase—if you get to the stage you can't make decisions for yourself who would you like to do that, and have you discussed this with them?</p> <p>Ask the question. In the event of you not being able to speak for yourself who would you like to speak for you. Have you spoken to this person? Not be evasive and use the word death or dying.</p>
Respecting the patient, their family and wishes	<p>My communication techniques with my patients and their family members so as to improve shared decision making and respecting their needs and improving end of life care.</p>
Separating the person from the illness	<p>Be aware that long standing illness is a trajectory to dying, it just takes time. Every time a patient is admitted with chronic illness, they are one phase closer to dying. Communicate openly, say the word dying, ask who they have to take care of their decisions if they are unable. Continually respect them as a person, never a disease.</p> <p>Ensure that patients are HEARD, that they are RESPECTED and that I am interacting with the PERSON—not simply a disease.</p>
Supporting the patient and family members	<p>Support people to have a better understanding of their current condition and what is being done medically as well as being able to talk about their wishes with family and loved ones.</p>
Taking time to be with the patient	<p>Let the person know I value them, giving them my time, patience and respect.</p>
Professional practice	
Advocacy for the patient	<p>To be in tune with the patient. To advocate and even educate less experienced staff about the signs of imminent death. To try to ensure that other health professionals including doctors don't miss these signs that the patient is displaying.</p>
Act quickly	<p>I can be aware of the need to respond urgently when things are not going well and escalate my response by being more open in my communication with those involved with the patient to get consensus in treatment. I can escalate the problem by sharing it with others who can better make the decisions for the care of the patient—in this instance for me the first step would be a discussion with an ECP or the patients treating team if they are available.</p>
Ask questions	<p>Ask questions of the medical professionals and seek more information so I can support the patient and family and be prepared.</p> <p>Ask the question, if you become very unwell, and are unable to make decisions on your own health, have you chosen someone who can make those decisions for you? Do they know about it?</p> <p>Listen to the patient or client. Really hear what they are saying about their fears and concerns and then look at the diagnostics. Ask questions about pain, nausea and emotional concerns.</p>
Identify end-of-life triggers	<p>Will not miss any opportunity to start/create conversations and discuss patients/family's needs, goals and dying. Will think of communicating about EOL as 'telling the truth with kindness' rather than 'breaking bad news'. Will listen generously to patient/families cues, triggers and questions. Will use the available tools and triggers and be creative in adopting and adapting the appropriate approaches in communication.</p> <p>I have an understanding off the trajectory of illnesses. Using this I can have a basic understanding on how to explain the illness process to family and the patient. Using triggers to identify patients who may be heading towards end of life and beginning the conversation with the family and patient earlier rather than days prior to death.</p>
Including patients and families in the team	<p>Recognize that you are not alone you work as a team. Respect patients' wishes and need to know their disease and their prognosis. Involve the family members in decision making. Set up family meeting with the multidisciplinary team. Listen and spend time with the patient then you will be able to gather information that are vital to patients well being.</p>
Leadership	<p>Effective teamwork encompasses leadership, clear goals, clear roles, trust, respect and a cultural readiness to allow patients to steer care.</p>

raised as a barrier in a study with 533 Malaysian hospital nurses including the difficulties inherent in discussions with patients and families,²¹ evidenced in our study via a subtheme of ‘curb my own avoidance’.

Emotional insight

Emotional insight, which is missing from the Consensus Statement elements, was an important emerging theme, including discussions of prerequisites that enable safe and quality care to flow. The professional and, arguably, human virtues that respondents say are important when working in large bureaucracies include compassion, empathy and honesty, which are inherent in end-of-life care.²³ HCPs in generalist areas are often unfamiliar with the importance of acknowledging the often strong emotions of others (staff, patients, families), and can more easily struggle with their own emotions, becoming susceptible to burnout.²⁴ For example, it was insightful that some respondents were concerned that their own emotions would impact or over-ride that of the patients in emotional situations.²⁵

Professional mindset

Expected deaths will continue to occur in hospitals and it is important that HCPs providing care strengthen their knowledge, confidence, open-mindedness and skills to provide best practice end-of-life care.³ The term ‘silent witnesses to care’, although in relation to student nurses in Canada facing difficult end-of-life situations where they feel unprepared and powerless to effectively engage with patients and families,²⁶ arguably applies to many HCPs.

Person-centred care

Person-centred care sees HCPs acknowledging the patient as a partner in care planning and decision-making.²⁷ In our study, respondents recognised the need to respect the wishes of patients and families, to support them and to take time to be with them. Sharma and colleagues²⁸ indicate the need to get to know the person which has come across in our study as the need to separate the person from the illness. With an emphasis on patient-centred approaches to care, advocacy roles can be more easily facilitated as patients’ wishes and views are known,²⁷ and this came across in respondents’ intentions.

Professional practice

Interestingly, teamwork and the need to include patients/family as part of this was highlighted, tying back again into person-centred care, which in turn is seen as integral to collaborative end-of-life care.²⁹ Acute care clinicians can recognise dying, although this does tend to be at a late stage,¹¹ so unsurprisingly this is conveyed in the results as the need for ‘triggers’, ‘trajectories’ and ‘tools and resources’ to help with this.

PRACTICE CHANGE

It is important to note that intent-to-change practice, a form of human behaviour,³⁰ cannot be measured in this study;

however, theory on intention-behaviour relations indicates that intentions have a strong association with behaviour, and that the greater control we have over our behaviour the more likely it is that change will follow.³¹ The EOLE education is targeted at individual HCPs, recognising that this is the level at which they have most control, and in recognising that systems change is required to improve dying in hospitals.³² While HCPs self-select into the education and are empowered to improve their own practice, influencing change or implementing new initiatives even at a local level can be challenging, dependent on the culture of the team and work setting.³³

IMPLICATIONS

People are living longer than ever before, often at the cost of living with debilitating multiple comorbidities requiring complex care or interventions (likely to require hospitalisation), which may well result in end-of-life care.^{12 34} The rhetoric around dying is that it is everyone’s business,³⁵ but care of the dying in hospitals is undertaken by HCPs who are unlikely to have palliative care experience; be working in organisations that integrate a palliative approach to care,³⁶ or necessarily refer to (or have access to) specialist palliative care.³⁷

This study demonstrates the complex emotional nature of the end-of-life care work³⁸ and its impact on the workforce at an individual, team and organisational level.³⁹ Educators, managers, policy writers and government should appreciate the complexity of this type of care and, wherever possible, acknowledge, promote and support the workforce.⁴⁰

FUTURE

Education is vital, however alone it does not bring about change.⁴¹ For EOLE, this is achieved in part by offering the education in conjunction with an implementation toolkit that provides learners with practical ways in which they can change their practice in an ongoing manner.¹⁴ Whether this change is sustainable in practice is still yet to be understood and this is an area open to further investigation.

It is also envisaged that timely reminders can be built into the learning management platform to prompt further module completion and engagement.⁴² The feasibility of local change champions is also under investigation, to support learners in practice and improve quality care.⁴³ There is also the need to directly ask learners who have completed the education about challenges to practice change, and an evaluation is currently underway to address this via an online survey and semistructured interviews.

Hospitals are complex bureaucracies which will need complex multifaceted drivers for change. Our research shows that, with education, individual clinicians can devise appropriate and honourable change elements for their practice. In addition, the ACSQHC has integrated these Elements of Processes of Care (used as the foundation of EOLE) into the National Safety and Quality Health Service Standards, Second Edition, thus elevating

comprehensive care into the accreditation processes. Hospitals are now required to provide evidence in a quality assurance mechanism on end-of-life care.

LIMITATIONS

Of the 5181 learner registrations, we received 3200 responses to the particular question. Answering the question was voluntary. However, the same kind of question was posed at the end of all six modules and respondents could have opted out, with questions viewed as repetitive if modules were taken sequentially. There are also limitations in that this is a self-report measure and learners may be motivated to change practice at the end of the education but less motivated when faced with any barriers to actual practice change. Practice change is governed by many drivers and barriers, including, but not exclusive to, workplace culture, policies and procedures, staffing numbers and mix of disciplines, and funding arrangements. We have reported on one element of a complex system—how individual staff identified how they can change their own practice.

Learners are also responding to a single question raised at the end of a learning module, where they could easily quote what they had just learnt, without critically analysing what it actually means for patient care. Some may well have done this, but others have looked closely to how they can change their clinical practice.

While the concepts highlighted in the education modules predetermine to some extent the results, the themes that emerged in coding were initiated by a research assistant with no prior knowledge of the module content.

CONCLUSION

The EOLE education modules have been well received and self-reported practice change intentions indicate how clinical care can be improved. This study also serves to demonstrate how the Consensus Statement, as a guide to improve quality and safety and the education derived from it, can influence an intent by HCPs to change attitudes, behaviour and practice, which in turn impacts end-of-life care and the patient experience. We report tangible actions and moral dimensions that provide a foundation to quality end-of-life care. These practice change actions and dimensions can provide examples for other clinicians who are keen to improve practice. The findings are also valuable to organisations and policymakers who can support positive change in workplace culture and are wanting to change healthcare outcomes and improve the quality of dying in hospitals. The human virtues of honesty, compassion, dignity and empathy are central to quality end-of-life care in our hospital systems and these virtues can be implemented into practice.

Acknowledgements Georgia Middleton is acknowledged for her work in data analysis.

Contributors KD and NP were involved in the original project conception and grant. KD developed the education modules. DR and KD conceptually developed the

paper, which was drafted by DR. All authors commented on, reviewed and approved the final draft.

Funding EOLE is funded by the Australian Government Department of Health.

Disclaimer The funding body and ACSQHC have no role in the development or writing of the article.

Competing interests KD and DR have received salary funding from the End of Life Essentials (EOLE) project. NP is employed by the Australian Commission on Safety and Quality in Health Care (ACSQHC).

Patient consent for publication Not required.

Ethics approval Ethics approval for the project was granted by the Social and Behavioural Research Ethics Committee at Flinders University, Adelaide, South Australia (Project 7012).

Provenance and peer review Not commissioned; internally peer reviewed.

Data sharing statement Data are available upon reasonable request.

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REFERENCES

1. Australian Commission on Safety and Quality in Health Care. *National Consensus statement: essential elements for safe and high quality end-of-life care*. Sydney: ACSQHC, 2015.
2. Swerissen H, Duckett S. Dying well. Grattan Institute. Victoria, Australia; 2014.
3. Reid C, Gibbins J, Bloor S, *et al*. Healthcare professionals' perspectives on delivering end-of-life care within acute hospital trusts: a qualitative study. *BMJ Support Palliat Care* 2015;5:490–5.
4. Hardy JR, Good P. A good death in hospital. *Intern Med J* 2014;44:313–4.
5. Al-Qurainy R, Collis E, Feuer D. Dying in an acute hospital setting: the challenges and solutions. *Int J Clin Pract* 2009;63:508–15.
6. Witkamp FE, van Zuylen L, Borsboom G, *et al*. Dying in the hospital: what happens and what matters, according to bereaved relatives. *J Pain Symptom Manage* 2015;49:203–13.
7. Verhofstede R, Smets T, Cohen J, *et al*. End-of-life care and quality of dying in 23 acute geriatric hospital wards in Flanders, Belgium. *J Pain Symptom Manage* 2017;53:693–702.
8. Virdun C, Luckett T, Lorenz K, *et al*. Dying in the hospital setting: a meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important. *Palliat Med* 2017;31:587–601.
9. Virdun C, Luckett T, Davidson PM, *et al*. Dying in the hospital setting: a systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. *Palliat Med* 2015;29:774–96.
10. Bloomer M. The challenges of end of life care in acute hospitals. *Collegian* 2015;22:241–2.
11. Australian Commission on Safety and Quality in Health Care. *Safety and Quality of End-of-life Care in Acute Hospitals: A Background paper*. Sydney: ACSQHC, 2013.
12. Gunasekaran B, Scott C, Ducharlet K, *et al*. Recognising and managing dying patients in the acute hospital setting: can we do better? *Intern Med J* 2019;49:119–22.
13. Hillman KM. Failure to recognise patients at the end of life in acute hospitals. *Acta Anaesthesiol Scand* 2014;58:1–2.
14. Hutchinson C, Tieman J, Devery K. Evaluation of a toolkit resource package to support positive workplace behaviours in relation to quality end-of-life care in Australian hospitals. *BMJ Open Quality* 2018;7:e000286.
15. Patton M. *Qualitative Research and Evaluation Methods: integrating theory and practice*. 4th edition. SAGE Publications, 2015.
16. Azungah T. Qualitative research: deductive and inductive approaches to data analysis. *Qual Res J* 2018;18:383–400.
17. Liamputtong P, Ezzy D. *Making sense of qualitative data: Analysis process*. In: *Qualitative research methods*. 2nd ed. South Melbourne: VIC Oxford University Press, 2015: 257–85.
18. Pope C, Ziebland S, Mays N. Qualitative research in health care: analysing qualitative data. *BMJ* 2000;320:114–6.
19. Hales S, Zimmermann C, Rodin G. Review: the quality of dying and death: a systematic review of measures. *Palliat Med* 2010;24:127–44.

20. Becker CA, Wright G, Schmit K. Perceptions of dying well and distressing death by acute care nurses. *Appl Nurs Res* 2017;33:149–54.
21. Hussin EOD, Wong LP, Chong MC, et al. Nurses' perceptions of barriers and facilitators and their associations with the quality of end-of-life care. *J Clin Nurs* 2018;2:e688–702.
22. Hancock K, Clayton JM, Parker SM, et al. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med* 2007;21:507–17.
23. Zaman S, Whitelaw A, Richards N, et al. A moment for compassion: emerging rhetorics in end-of-life care. *Med Humanities* 2018;44:140–3.
24. Gama G, Barbosa F, Vieira M. Personal determinants of nurses' burnout in end of life care. *Eur J Oncol Nurs* 2014;18:527–33.
25. Bailey C, Murphy R, Porock D. Professional tears: developing emotional intelligence around death and dying in emergency work. *J Clin Nurs* 2011;20:3364–72.
26. Doucette E, Killackey T, Brandys D, et al. Silent witnesses: Student nurses' perspectives of advocacy and end-of-life care in the intensive care unit. *Dynamics* 2014;25:17–21.
27. Moore L, Britten N, Lydahl D, et al. Barriers and facilitators to the implementation of person-centred care in different healthcare contexts. *Scand J Caring Sci* 2017;31:662–73.
28. Sharma T, Bamford M, Dodman D. Person-centred care: an overview of reviews. *Contemp Nurse* 2015;51:107–20.
29. Pfaff K, Markaki A. Compassionate collaborative care: an integrative review of quality indicators in end-of-life care. *BMC Palliat Care* 2017;16:1–24.
30. Eccles MP, Hrisos S, Francis J, et al. Do self-reported intentions predict clinicians' behaviour: a systematic review. *Implementation Sci* 2006;1.
31. Webb TL, Sheeran P. Does changing behavioral intentions engender behavior change? A meta-analysis of the experimental evidence. *Psychol Bull* 2006;132:249–68.
32. Clark K, Collier A, Currow DC. Dying in Australian hospitals: will a separate national clinical standard improve the delivery of quality care? *Aust. Health Review* 2015;39:202–4.
33. Rawlings D, Devery K. What is the impact of postgraduate palliative care on students' ability to effect practice change. *Aust J Adv Nurs* 2018;36:16–24.
34. Jelinek GA, Marck CH, Weil J, et al. Skills, expertise and role of Australian emergency clinicians in caring for people with advanced cancer. *BMJ Support Palliat Care* 2015;0:1–7.
35. Bartel R. *Conversations: creating choice in end of life care*. Melbourne: Australian Centre for Health Research (ACHR), 2016.
36. Sawatzky R, Porterfield P, Lee J, et al. Conceptual foundations of a palliative approach: a knowledge synthesis. *BMC Palliat Care* 2016;15:51–5.
37. Firn J, Preston N, Walshe C. What are the views of hospital-based generalist palliative care professionals on what facilitates or hinders collaboration with in-patient specialist palliative care teams? A systematically constructed narrative synthesis. *Palliat Med* 2016;30:240–56.
38. Rose J, Glass N. An Australian investigation of emotional work, emotional well-being and professional practice: an emancipatory inquiry. *J Clin Nurs* 2010;19:1405–14.
39. Hayward RM, Tuckey MR. Emotions in uniform: how nurses regulate emotion at work via emotional boundaries. *Human Relations* 2011;64:1501–23.
40. Gagnon J, Duggleby W. The provision of end-of-life care by medical-surgical nurses working in acute care: a literature review. *Pall Supp Care* 2014;12:393–408.
40. National Institute for Health and Clinical Excellence (NICE). *How to change practice*. London: National Institute for Health and Clinical Excellence, 2007.
42. Anderson T, Dron J. Integrating learning management and social networking systems. *Ital J Educ Technol* 2017;25:5–19.
43. Witkamp FE, van Zuylen L, van der Rijt CCD, et al. Effect of palliative care nurse champions on the quality of dying in the hospital according to bereaved relatives: a controlled before-and-after study. *Palliat Med* 2016;30:180–8.