Dying, a normal part of life: what learners see as the one thing they could change in the workplace to more appropriately provide end-of-life care

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Authors

MS DEB RAWLINGS

BSc (Hons) Nurs., MPH. Senior Lecturer and Course Coordinator in Palliative Care, Palliative and Supportive Services. Deb is an inaugural member of the Flinders University Research Centre in Palliative Care, Death and Dying. She has nearly 30 years' experience in Palliative and End of Life Care. Deb has worked in both oncology and palliative care nursing and been involved with several Commonwealth funded projects, including End-of-Life Essentials on which she is a co-investigator.

ASSOCIATE PROFESSOR KIM DEVERY

BSocSc (honours) UNSW. Academic Lead, Palliative and Supportive Services, Flinders University. The group is internationally recognised for its postgraduate courses in palliative care. Kim is an inaugural member of the Flinders University Research Centre in Palliative Care, Death and Dying. She has been involved in a number of national education projects in palliative care, including leading a major national education and knowledge translation project End-of-Life Essentials.

PROFESSOR JENNIFER TIEMAN

BSc(Hons), MBA, PhD, FAIDH. Professor Tieman is a Matthew Flinders Fellow and the inaugural Director of the RePaDD Centre in the College of Nursing and Health Sciences, Flinders University. She is also CareSearch Director and in this role leads a series of national research projects in palliative care and aged care. Professor Tieman is a Foundational Fellow of the Australian Institute for Digital Health.

MRS MEGAN WINSALL

BSc, Grad Dip PH. Research Officer, Palliative and Supportive Services, Flinders University. Megan has been involved in several different research projects at Flinders University, in the fields of mental health, health informatics, aged care, and palliative care. She currently provides research assistance to the End-of-Life Essentials project.

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About this White Paper

This publication is a RePaDD White Paper and Research Report.

The RePaDD White Paper and Research Report Series provide researchers and policy makers with evidence-based data and recommendations. By organising, summarising and disseminating previous and current studies, the series aim to inform ongoing and future research in palliative care, death, and dying.

Contact

Enquiries regarding this White Paper and Research Report should be directed to the lead author, Deb Rawlings

Phone: 61 87221 8215
Email: deborah.rawlings@flinders.edu.au

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Acknowledgement of Country

Flinders University was established on the lands of the Kaurna nation, with the first University campus, Bedford Park, located on the ancestral body of Ngannu near Warriparinga.

Warriparinga is a significant site in the complex and multi-layered Dreaming of the Kaurna ancestor, Tjilbruke. For the Kaurna nation, Tjilbruke was a keeper of the fire and a peace maker/law maker. Tjilbruke is part of the living culture and traditions of the Kaurna people. His spirit lives in the Land and Waters, in the Kaurna people and in the glossy ibis (known as Tjilbruke for the Kaurna). Through Tjilbruke, the Kaurna people continue their creative relationship with their Country, its spirituality and its stories.

Flinders University acknowledges the Traditional Owners and Custodians, both past and present, of the various locations the University operates on, and recognises their continued relationship and responsibility to these Lands and waters.

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The Research Centre for Palliative Care, Death and Dying (RePaDD)

Death and dying will affect all of us. The Research Centre for Palliative Care, Death, and Dying or RePaDD works to make a difference to the care of persons at the end of life.

We examine the universal experience of dying and create innovative solutions for people living with a life-limiting illness, their carers, and the clinicians caring for them.

Our members lead major national palliative care projects in Australia. Our team of multidisciplinary researchers and experts work collaboratively with various organisations and funding agencies to deliver impact. We also strengthen research capacity by offering evidence-based resources, researcher education, and training and scholarships.

Our research

We focus on the following research areas:

Palliative care across the health system: We conduct clinical and service studies and develop online palliative care resources and applications. Our work in this area contributes towards ensuring that quality palliative care can be delivered in all healthcare settings - whether in hospitals, aged care, homes, hospices, clinics or the community.

Death and dying across the community: We examine and respond to community and consumer attitudes, views, and needs with respect to death and dying and palliative care. Our research in this area empowers the wider community to make informed decisions by raising awareness and building death literacy.

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Executive Summary

End-of-Life Essentials (EOLE) is a government funded project which aims to provide free peer-reviewed online education modules and implementation resources on end-of-life care to health professionals in acute hospitals in Australia. 'Dying, A Normal Part of Life' is an educational module featured in the suite of EOLE modules and includes education around the impact of end of life and dying on health care professionals working in acute hospitals, identifying common patterns of trajectories of dying, and discussing the reasons why dying in acute hospitals is often complex for professionals, patients, and families.

This White Paper outlines and explores the results of the retrospective data analysis conducted for a two year period, 6th May 2017 to 5th May 2019. A total of 2232 learner statements responding to the free text response question posed at the end of the module: *"Tomorrow, the one thing I can change to more appropriately provide end-of-life care is…"* were extracted from the EOLE learning platform. The results identified the following themes as nominated practice change areas:

1. Patient-centered care
2. Communication skills
3. Humanising healthcare
4. Recognise and talk about dying
5. Organisational factors

Each theme contained separate subthemes.

Study findings show that this foundational module generated themes that are common to many other modules in the EOLE education and reflect the essence of what is required to provide good quality end-of-life care in hospitals. With the population trends facing Australia over the next 25 years, where the number of deaths annually will double, workforce planning and increasing the capacity of providing quality end-of-life care is crucial.[1]

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Introduction

End-of-Life Essentials (EOLE) is a government funded project which aims to provide free peer-reviewed online education modules and implementation resources on end-of-life care to health professionals in acute hospitals in Australia.[2] EOLE has been developed in recognition that end-of-life care in hospitals needs to be improved.[3] The hospital environment is fast paced, with a focus on restoring health and curing illness. Hospitals are also the place where over half of all deaths occur in Australia.[1] The hospital workforce is not well trained in end-of-life care, or skilled in recognising expected dying or negotiating goals of care. The need for EOLE has also been driven by Australia's population trends, an ageing population who are increasingly living with and dying from, chronic disease or several chronic complex illnesses.[4] Most Australian will die from a combination of the leading causes of death: coronary heart disease, dementia (including Alzheimer's disease), cerebrovascular disease, lung cancer and Chronic Obstructive Pulmonary Disease (COPD).[5]

EOLE is based on the Australian Commission on Safety and Quality in Health Care (ACSQHC) National Consensus Statement: essential elements for safe and high-quality end-of-life care.[6] The project translates the five processes of care elements from the statement: patient centred care; teamwork; goals of care; using triggers; responding to concerns, directly into a suite of (currently) ten education modules and an associated toolkit, developed with input and review of industry stakeholders.[3, 6] Ongoing evaluation has been built into the education modules to detect changes in learner responses before and after they engage with the modules, as well as answers to tailored questions posed at the end of each module.[3]

'Dying, A Normal Part of Life' features in the suite of EOLE modules and includes education around the impact of end of life and dying on health care professionals working in acute hospitals, identifying common patterns of trajectories of dying, and discussing the reasons why dying in acute hospitals is often complex for professionals, patients and families.[7] The learning outcomes for this education module are:

1. Explain end of life and dying and the impact on health care and professionals who work in acute hospitals.
2. Identify common patterns or trajectories of dying.
3. Locate reasons why dying in acute hospitals is often complex for health professionals, patients and families.

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4. Appreciate your attitudes of and skills in end-of-life care.
5. Locate and appreciate helpful policy documents and other available resources.

The purpose of this study was to explore learner responses to the question posed at the end of the Dying, A Normal Part of Life module: *"Tomorrow, the one thing I can change to more appropriately provide end-of-life care is…"* This work is an extension of the earlier work undertaken on evaluation of this module.[3] Through using the same question across a different time period, this study provided an opportunity for a more in-depth exploration of this foundational module.

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Methods

Sampling

Participants in this evaluation were learners (healthcare professionals) who had accessed the EOLE website and engaged with the Dying, A Normal Part of Life module.

Data extraction and cleaning

Data were extracted for a 2-year period, 6th May 2017 to 5th May 2019.

A total of 2232 learner statements (one statement per learner) responding to the free text response question posed at the end of the module: *"Tomorrow, the one thing I can change to more appropriately provide end-of-life care is…"* were extracted from the EOLE learning platform. The data were cleaned, de-identified, and imported into NVivo 12 software package.

Data analysis

Data were analysed using NVivo 12. Thematic content analysis was conducted to identify key themes emerging from the data, a method chosen due to its suitability for analysing data on complex healthcare phenomena.[8, 9] Author MW completed coding for all data and created a coding scheme. An inductive, open approach was used to code the participant statements line-by-line, conceptually grouping similar words and sections of text, and adding new codes when new concepts emerged.[10] Axial coding was then used to organise the codes into overarching categories, and to develop and refine the themes.[10]

To add rigor and improve reliability,[9] authors MW and DR reviewed and discussed the analysis process and coding schema in detail, with subsequent minor modifications to the themes made.

Ethics approval

The project received approval from the Flinders University Research Ethics Committee (Project number: 7012).

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Results

Learner responses were organised in to five overarching themes, with each theme containing separate subthemes. Descriptions of each theme and subtheme, along with example quotes from participants, and a quantitative summary of the counts of codes identified in the analysis, are presented below.

Table 1. Number and percentage of learner statements related to each theme and subtheme

Theme/subtheme	No. learners (n=2232)	% learners
Patient-centred care	**804**	**36.0**
Discuss end of life care plans	358	16.0
Facilitate patient decision-making; prioritise and advocate for patients' needs and wishes	289	12.9
Provide information, answer questions	131	5.9
Coordination and continuity of care	92	4.1
Prioritise patient comfort; pain and symptom management	67	3.0
Communication skills	**783**	**35.1**
Listen	417	18.7
Openness and honesty	281	12.6
Adapt communication styles; 'able' responses	182	8.2
Humanising healthcare	**552**	**24.7**
Emotional support and empathy	377	16.9
Take the time	179	8.0
Ensure respect and dignity	101	4.5
Recognise and talk about dying	**550**	**24.6**
Confident in approach, initiate the conversation	226	10.1
Use words 'death' 'dying'	157	7.0
Don't avoid it, be open to it, normalise it	100	4.5
Don't be afraid	96	4.3
Recognise end of life	90	4.0
Organisational factors	**196**	**8.8**
Improve clinical skills, education, and training	147	6.6
More staff and resources	51	2.3

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1. Patient-centered care

A large proportion of learners (36.0%) valued a patient-centred approach to care, including discussing end of life care plans and providing information to patients, facilitating shared decision making and prioritising the needs and wishes of patients and their family, ensuring continuity of care, and prioritising pain and symptom management.

1.1 Discuss end-of-life care plans

Learners noted the importance of engaging in and encouraging patients and families to have conversations about end-of-life care, including advanced care plans and directives, and different treatment/care options, goals and wishes.

"Discuss goals of care and priorities for both the patient and family."

"Ask the question, should you become more sick- have you thought about who would be able to speak on behalf of yourself if you were unable to communicate your needs."

"To be prepared to talk with a patient about where they think they are at, to consider decisions and talking about end-of-life choices, and to ask if they have someone to talk with about choices and decision about end of life care"

1.2 Facilitate patient decision-making; prioritise and advocate for patients' needs and wishes

Learners discussed the need to understand, support and advocate for the wishes, needs, and choices of the patient and family, ensuring patients have active input in their own care.

"Advocating for the patient with doctors and other health care professionals if they aren't listening to the patient's wishes. advocating for the patient even within their own families"

"respect and understand the needs of the patient to want more input in their care."

"Providing family members with greater control and involvement with end-of-life care"

"To provide responsive and flexible care tailored to each patients specific needs"

1.3 Provide information, answer questions

Learners discussed answering patient questions and providing accurate information to patients and families regarding their condition, prognosis and care. This included referring them on to outside services if necessary.

"To be more open to answering questions about dying and giving the patient the opportunity to ask questions about what is happening to them"

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"If I am unable to answer to not just let it go but to follow through or find someone who will be able to explain better."

"Not brushing off a pt's question about their prognosis - ensuring that they are given true and honest information about the progress of their illness."

1.4 Coordination and continuity of care

Learners discussed the importance of keeping patients, families, and clinicians on the same page regarding end of life care plans and goals e.g. ensuring continuity of care, working as a team to coordinate care, and taking a multidisciplinary approach.

"Have open and honest conversations within the clinical team to common goals in working appropriately towards providing collaborative end of life are options to patients"

"Encourage all team members to provide consistent information to the patient"

"greater communication throughout the team for a more comprehensive response"

1.5 Prioritise patient comfort, pain and symptom management

Learners discussed making patient comfort and pain and symptom management a priority when caring for someone at the end of life.

"offer them support that we will be treating the symptoms of dying and make them as comfortable as possible."

"Is to always make the patient as comfortable and pain free as possible."

"avoiding futile investigations and treatments"

2. Communication skills

A large proportion of learners (35.1%) commented on good communication skills being important in end-of-life care, including listening, being open and honest, and adapting communication styles to meet the needs of patients and family.

2.1 Listen

Learners discussed the importance of effectively and actively listening to the patient.

"Listen to what the patient is saying"

"Be a better listener"

"I really like the idea of taking time to "hear" the patient's concerns and allowing time for silence after they have spoken to let them think and have their feelings "sink" in to what they have said. I like learning to listen longer before speaking."

2.2 Openness and honesty

Learners discussed the importance of taking an open and honest approach

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when communicating with patients and families.

"be honest with patients and families."

"Not provide any false hope, or mislead a patient into thinking that they are not as sick as they really are."

"is a more open, honest and transparent dialogue between patients and medical professionals in regards to end of life care,"

2.3 Adapt communication styles; 'able' responses

Learners made comments on the use of plain language, speaking with clarity, adapting communication styles and phrases as needed, and the use of 'able' responses when speaking with the patient and family.

"Talking to clients and their families is a simple easy to understand way"

"Use the language that the patient is using to discuss their fears & concerns"

"To improve how I communicate to patients and family"

3. Humanising healthcare

24.7% of learners expressed the importance of taking a humanistic and holistic view of the patient and family, seeing them as people rather than just treating their disease. Elements of this included providing emotional support

and empathy, taking the time to be with the patient, and ensuring respect and dignity during all aspects of patient care.

3.1 Emotional support and empathy

Learners discussed providing emotional support, reassurance and comfort to patients and their families, including the use of empathy and compassion, and actively discussing and acknowledging fears, concerns, and emotions.

"Being more compassionate"

"To show that each of my patient(s) is of vital concern to me & that their treatment & care is personal to myself to show empathy & genuine concern."

"Be in touch with patient's feelings and worries that the current exacerbation of his / her chronic illness is very frightening for him / her; sit down with patient and acknowledge their fears about dying"

3.2 Take the time

Learners acknowledged the importance of taking the time and having enough time to be with the patient, talk with the patient, and to be present and available to meet the needs of the patient and family.

"Take my time and be present"

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"take the time to have meaningful conversations"

"I do realise I sometimes do "rush" and should allocate more time"

3.3 Ensure respect and dignity

Learners highlighted the importance of treating the patient and family members with respect and maintaining the patient's dignity.

"How I treat people, treating all with the respect and dignity that I would like to be shown"

"ensure that patients are treated as human beings (rather than 'dying' patients) throughout their care."

"give all the time a patient needs to feel like they have been listened to, respected and treated as a person rather than a diagnosis."

4. Recognise and talk about dying

24.6% of learners emphasised the importance of talking about death and dying, e.g., starting the end-of-life conversation, confidence around the topic and not being afraid of or avoiding it, as well as actively using the words 'death' and 'dying'. Learners also discussed the need to be able to accurately recognise when a patient was approaching their end of life.

4.1 Confidence in approach; initiate the conversation

"Have more confidence to approach end of life conversation with patients"

"Start end of life discussions early"

4.2 Use words 'death' and 'dying'

"Using the word ' death ' or 'dying ' in conversation with patient / family"

"Not avoid the words 'death' or 'dying' in conversations with palliative residents, in discussions with care staff, or with family members."

"Being able to comfortably use the word death or dying instead of sugar coating."

4.3 Don't avoid it; be open to it; normalise it

"Is to be more open in my discussion about death and dying and not shy away or pretend that it is not going to happen."

"A change in attitude about death from unspeakable to inevitable."

"Acknowledge death as a natural process in life."

4.4 Don't be afraid

"Not to be afraid of talking about dying."

"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

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doesn't have to be something to be frightened of talking about."

"By overcoming my fears and discomfort on this topic."

4.5 Recognise end of life

Learners discussed the need to be able to accurately recognise when a patient was approaching their end of life, e.g. through recognising physical signs and symptoms, understanding the patients' condition, and understanding common disease trajectories.

"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."

"Understanding the signs and symptoms of end of life"

"Recognising that it may be time to have a conversation about end of life"

5. Organisational factors

8.8% of learners discussed factors relating to their organisation or workplace, including opportunity for education and clinical skill development, and resources.

5.1 Improve clinical skills, education, and training

Learners recognised the need to improve their own and other staff members' clinical skills when it came to end of life care, e.g., through participating in relevant education and training.

"Try and improve my skills regarding end of life care."

"more open and available education about end of life treatment across all wards"

"More training on how to actually speak to patients and their families about dying (as covered in this unit) and also on the importance of holistic care in palliative care settings."

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5.2   More staff and resources

Learners expressed a need for more funding, increased staff-patient ratios, and more beds dedicated to end of life/palliative care.

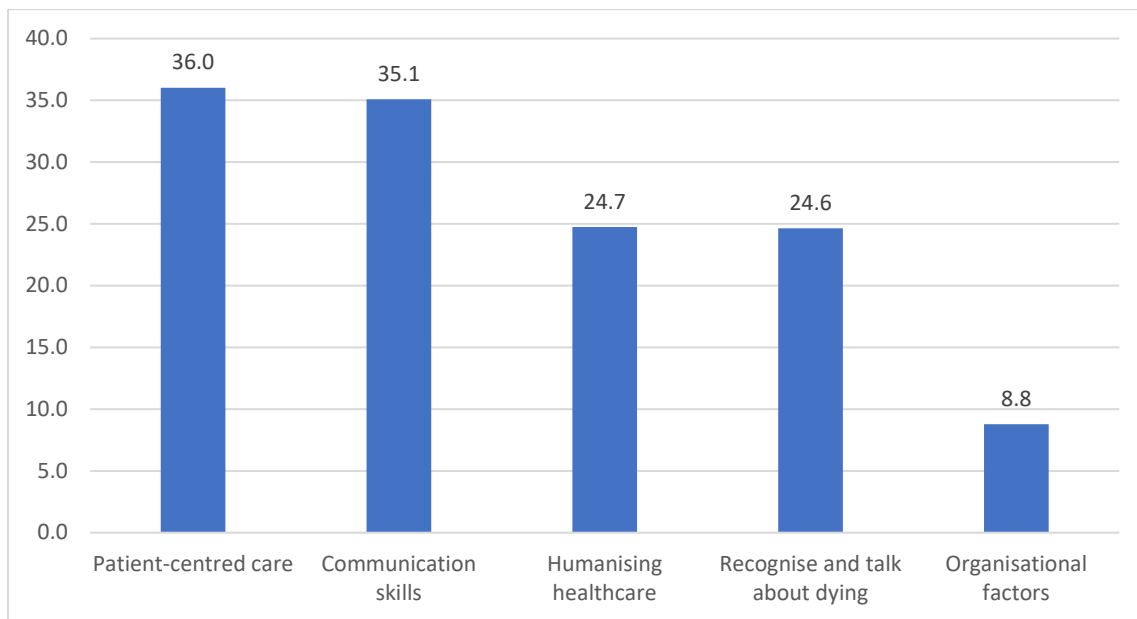*"To have more staffing in end-of-life care for support when needed for patients and family."*

"Not have patients with terminal illnesses die in emergency departments due to unavailability of beds in ward."

"Extra staff to give more time to being able to have conversations without rushing"

Figure 1. Word Cloud - All Data

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Figure 2. Percentage of learner statements relating to each major theme

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Discussion

This study is an extension of earlier work undertaken in relation to evaluation of this module,[3] and while using the same question, has collected data across a different time period. This study has therefore provided an opportunity of a more in-depth exploration of the impact of this foundational module. One result that became apparent was that the themes derived from the learner responses in the present study are not unique to the module Dying, A Normal Part of Life. Themes found here have been identified in other EOLE evaluation studies. For example, the Chronic Complex Illness module evaluation identified themes of: patient-centered care, communication skills and recognise and talk about dying (under discussing prognosis).[4] Furthermore, the conceptual theme of Humanising health care, was partially identified in the evaluation of the Imminent Death module, the theme of Humanising health care were also uncovered in the Emergency Department module evaluation (Rawlings et al 2021b). Organisational factors were highlighted also in previous work undertaken on practice change.[11]

We asked learners what the one thing was they could change in their practice tomorrow to more appropriately provide end-of-life care. The findings in this present study reflect the essence of what is required in the individual clinicians' practice change to provide good quality end-of-life care and is subsequently what clinicians have articulated that they need to address. Most health care professionals have no foundation skills in the themes that have been identified, as for example, communication skills or recognising and talking about dying are not often taught in undergraduate curricula. Hospital health care professionals are particularly skilled at acute care, in treating diseases and in restoring health, but opportunities to improve end-of-life care are often inadvertently missed, with many health care professionals unaware that this equates with high quality care. Professionally under-skilled in end-of-life care, clinicians may struggle and so purposely or inadvertently avoid identifying end of life or discussing goals of care that often may be highly emotional conversations. However, all health care professionals in acute hospitals need to be as responsive to end-of-life needs as they are to acute care scenarios, as every day the majority will encounter people who are dying.

Some of the suggestions provided by learners could be immediately implemented by individuals or within teams, while others would require structural or process changes but would have the result of helping to empower clinicians. We have found that the

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EOLE education modules are providing a vehicle for practice change.

The use of technology needs consideration, as EOLE uses data platforms to capture both qualitative and quantitative data embedded within modules, to measure the extent to which they improve knowledge, skills, and confidence, providing critical practice insights as well as indicators of intent to change practice as a result of learning.[12] The online learning platform facilitates access to the EOLE education modules, allowing learners to refresh their skills and clinical knowledge. A qualitative study undertaken by the EOLE team found that many health care professionals need clinical professional development to support end-of-life care, with many valuing lifelong learning, as well as the flexibility of the online environment; all of which can enhance confidence in end-of-life discussions.[13]

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Conclusion

Results from this retrospective analysis of qualitative learner statements highlight clinician's recognition of what they need to address in order to provide good quality end-of-life care in hospitals.

An important finding is that while this module is where the majority of learners start their EOLE learning and while it is taken by around one third of learners who register, the themes and concepts here are also identified across other modules. This is indicative of the importance of a patient-centered care approach, of good communication skills, of the importance of recognising dying, and all importantly, the need to humanise healthcare, looking to the fundamentals of quality care such as respect, dignity, taking the time, emotional support, and empathy.

Learners have taken away key messages from the education module and have made statements about what they can change in their practice. An important consideration is how this could then play into their scope of practice and scope of influence within the wider healthcare team, with the EOLE education modules providing a vehicle for practice change.

The number of Australians who die each year will double over the next 20 years.[1] The provision of safe and quality end-of-life care will increasingly be required across all hospitals and beyond. Having a confident workforce who can identify expected dying, engage and prioritise patient comfort, manage symptoms, communicate honestly and be responsive to increasing skills, education and training has been identified here by health care professionals. These capabilities will also meet the challenges of our future.

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