Dying, A normal part of life: What learners see as the one thing they could change in the workplace to enable quality end of life care

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Background

End of Life Essentials (EOLE) provides online learning opportunities and practice resources for health professionals to improve the quality and safety of end-of-life care in hospitals [1]

- EOLE is funded by the Department of Health.
- https://www.endoflifeessentials.com.au

- Purpose
- To identify the one thing health professionals would change in the workplace to enable quality end of life care as a result of completing this module -Dying, A normal part of life'

- Ethics approval was obtained from the Flinders University Research Ethics Committee (Project 7012).

Excerpts from the module

- This module sets the scene about end-of-life care in acute hospitals. We intend to describe how dying is a normal part of life and to identify clinical opportunities available to you to improve patient care
- Each and every patient you see in your workplace setting will die, at some time.

- Dying or end-of-life care has the potential to bring out the best and the most confronting health care.

- One of the tremendous successes of health care in the 20th century is the delay of death or prolongation of life, but health care cannot save life

Excerpts from the module: Your experiences

End-of-life care is challenging and it can be difficult to manage in our complex acute hospital system. It's challenging because, for example:

- You may never have had any undergraduate training in end-of-life issues.

- Acute hospital staff are very successful at treating disease and ingenious at restoring ill health but far less able to identify end of life or dying.

- For a variety of reasons, staff and patient conversations about end-of-life issues are sometimes avoided, missed or simply never planned.

Odds are that you have recently provided care or specific service to a patient who was dying from a progressive incurable illness; either a chronic complex condition like dementia, end-stage cardiac, renal or respiratory disease or cancer.

Excerpts from the module

- Dying, is a normal part of life - 52% of Australian die in acute hospitals [2]
- End of life may be months or even years or more before death.
- Knowing the common patterns or trajectories of illness can help you identify common normal courses of illness.
- Your conversations and skills can avoid a ‘freeway’ to ICU for many patients at the end of life.
- Understanding and growing your own capacity for end-of-life care skills can strengthen your practice.
- You can adapt and adopt responses to end-of-life conversations and situations.

Design

- The online learning module is based on a clinical scenario in an acute hospital setting. It is not for or about specialist palliative care.
- A free text question is posed at the end of the module asking about workplace change to improve the quality of dying.

  - **“If you could change one thing in your workplace to enable quality end of life, what would it be?”**

- Comments (n=2232) were received over a 2 year period (06 May 2017 to 05 May 2019– 05 May 2019).
- Learners were nurses, allied health professionals and doctors working in acute settings

Data handling and analysis

- The data were cleaned, de-identified, and imported into NVivo 12 software package. Thematic content analysis was conducted to identify key themes emerging from the data [3] a method chosen due to its suitability for analysing data on multi-layered healthcare phenomena [4,5]
- Responses were categorised into 15 themes

- **Talking about dying (n=525, 23.5%)**
- Listen (n=428, 19.2%)
- Emotional support & empathy (n= 377, 16.9%)
- Discuss end of life care plans (n=358, 16.0%)
- Person-centred approach (n=332, 14.9%)
- Openness and honesty (n=282, 12.6%)
- Good communication skills (n=183, 8.2%)
- Take the time (n=182, 8.2%)
- Improve clinical skills, educ & training (n=149, 6.7%)
- Provide information, answer questions (n=137, 6.1%
- Ensure respect & dignity (n=99, 4.4%)
- Coordination & continuity of care (n=91, 4.1%)
- Recognise end of life (n=88, 3.9%)
- Prioritise patient comfort (n=67, 3.0%)
- More staff & resources (n=51, 2.3%)

Death as a normal part of life

“We need to get rid of the stigma associated with death and change the cultural to a death accepting cultural from a death denying society”

“Encourage one another to be comfortable with the taboo word 'dying' and topic 'death.’”

“I believe that placing 'death and dying 'in its rightful place alongside 'life and living' within every conversation between patients and clinicians will begin to 'normalise' the conversations surrounding death, after all, every living being is going to die at some point and 'how' we want to do it should be at the centre of all care, everyone deserves the right to die with dignity, grace and peace, knowing that they made choices that are important to them”

Death as a normal part of life

“death needs to be normalised””

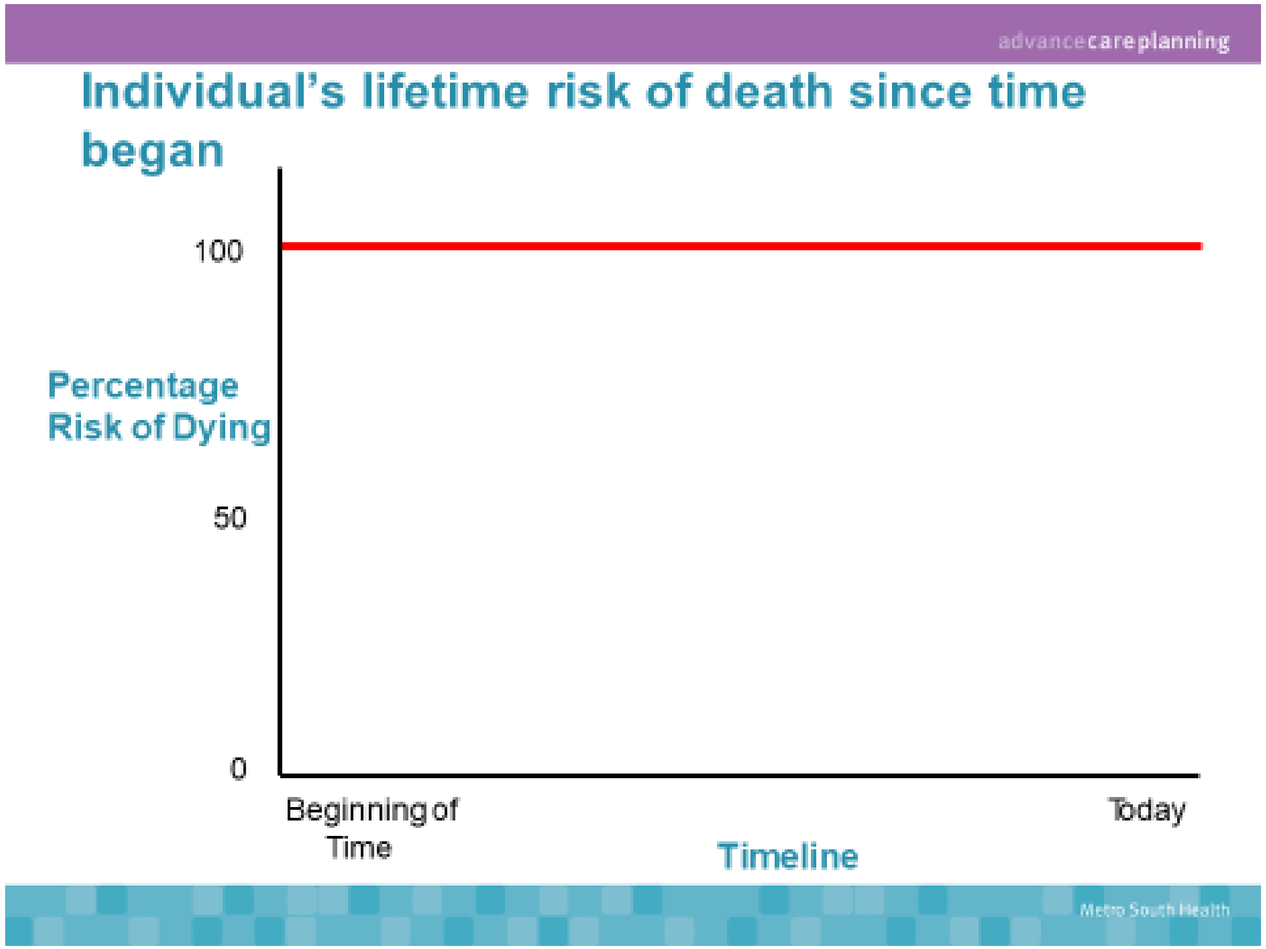
“see dying as a part if life which can be managed with care, dignity and respect”

“Speak about death and that it is a natural normal process”

“Dying is normal process of life”

“Acknowledge death as a natural process in life”

“is to accept that it is part of life and its okay to talk openly about it”



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Theme: Talking about dying

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’.

“Increase discussion between staff and patients about end of life.”

“treat dying as an ongoing process and don't be afraid to use the "d" word".

“To not shy away from a discussion around their end of life.”

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

Staff attitudes

"for the doctors and some nurse to understand that its okay for a patient to die, they also need to stop bringing in their own beliefs into the plan . not all patients who come into hospital need fixing they need CARE"

"educate all staff to assist in removing the stigma that death is a bad thing, embrace the end of life, it should be celebrated"

"All staff becoming comfortable and competent with end of life conversations"

"conversations with staff at ward meetings so it becomes normal to speak about death and that not all patients will go home"

It is difficult to have these conversations

- These conversations are difficult to have
- Words used to describe future actions / practice change include
  - Afraid (don't be afraid)
  - Brave (be brave)
  - Courage (have courage)
  - Avoid (don't avoid)
- Much of this is around the language of death and dying
- It speaks to the challenges in communication and or roles (responsibility) for having the conversations
- If not initiating, then know how to respond to a request /statement /question

Afraid (n=75)

“Not being afraid to use the word dying when someone brings it up”

“less afraid of causing distress when a patient wants to discuss the end of their life”

“don't be afraid in asking the uncomfortable questions”

“Not afraid of saying the word 'die’”

“Not to be afraid of using the word "die" or "dying"

Avoidance (n=54)

“Talk about dying. Don't avoid it as it's never gonna happen”

“Do not avoid talking about dying”

“To acknowledge that death is something to talk about and think about and not avoid the topic if it came up”

“if they ask about question re: dying, then to not avoid it”

“Stop avoiding the word 'die’”

Practice change intentions

"I will try to speak about end of life as a possibility that can't be denied or ignored while assuring the patient that we will provide the best possible care"

"Be confident and understanding when discussing EOL with patients. I will try not to be afraid to discuss dying with the patient"

"I will also not avoid the conversation"

"I will be able to converse with the patient and families about end of life"

Discussion

- With increasing numbers of people dying in hospital [2], optimising end-of-life care in this setting is vital.
- Having open and honest conversations is something that many HCPs either struggle with [6] or are unaware that this is wanted or required.
- The EOLE modules are improving knowledge, awareness, confidence and skills in end-of-life care, and are also providing a vehicle for promoting practice change.
  - These are self-reported and detail learners intent to change practice [7] rather than report on what they have done
- Some of the suggestions could be immediately implemented within the individual teams while others would require structural or process changes but would have the result of helping to empower individual clinicians.

I am not yet a registered nurse, but have one year left of my studies. I have however noticed on many of my placements in hospitals (and aged care) that often staff treat death and dying like taboo subjects. These topics are avoided or skirted around using indirect language. Palliative care is seen as a last resort saved for the very end of life, and is often not talked about until that time. Patients who are actively dying are treated by some staff as if they are very fragile, spoken to only in soft voices, and not joking or laughing around them ever. If I could change one thing, I would alter this attitude that death is taboo. I would ensure a better (and less fearful) understanding of end of life care, and ensure that patients are treated as human beings (rather than 'dying' patients) throughout their care.

Conclusion

- The organisational culture is for death and dying to be avoided
  - Acute care, cure focus
  - No recognition that death comes to us all
- We have become accustomed to using euphemisms to ‘soften’ the language of dying
  - Do not be afraid to use the words die, death, dying and engage in discussion about end of life, particularly when patients raise it

- The EOLE education modules have been well received and self-reported practice change intentions indicate how clinical care can be improved.
- Overall, our findings suggest that most learners thought they could change their practice for the better, nominating what they could do to improve appropriate care.

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