WHAT MATTERS - THE POWER OF THE PATIENT'S PERSPECTIVE IN DRIVING SAFE AND QUALITY DIGNITY IN CARE

Palliative Care Nurses Association Conference
2024

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The Australian Commission on Safety and Quality in Health Care (ACSQHC) has supported EOLE since it commenced in 2015.

Reminder – how we die

End-of-Life Essentials
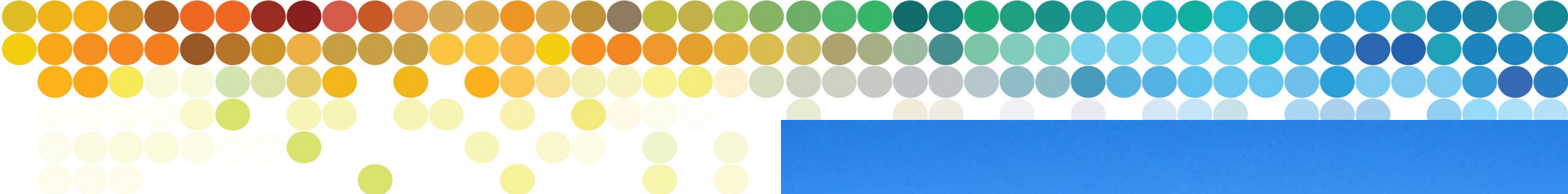
The importance of the Patient's perspective

Animation

Implications for practice

What do we die of?

AIHW 2021
Leading Causes of Death

2022 Covid was the third leading cause of death - ABS

1. CORONARY ARTERY DISEASE

2. DEMENTIA AND ALZHEIMER'S DISEASE

3. CEREBROVASCULAR DISEASE

4. LUNG CANCER

5. CHRONIC OBSTRUCTIVE PULMONARY DISEASE

Leading Causes of Death

Where we die

Place of death 2019

■ Hospital ■ RACF ■ Home ■ Other ■ Unspecified

Hospital 51%
RACF 30%
Home 15%
Unspeci... 3%
Other
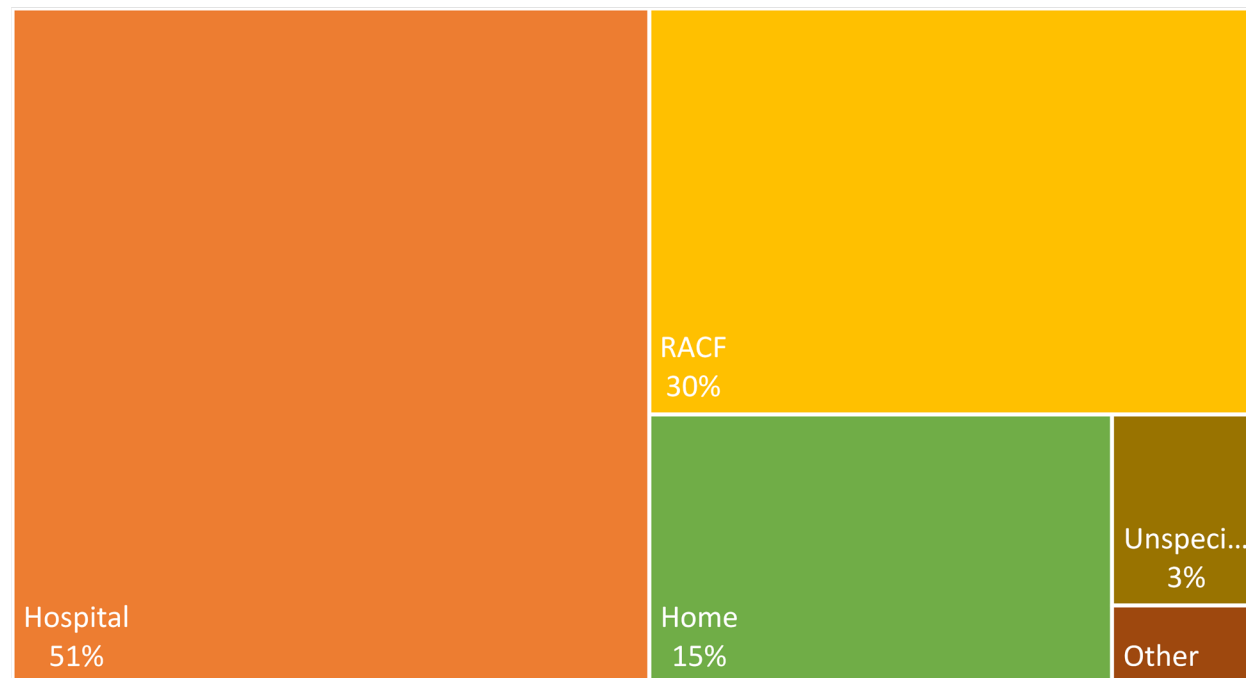
ABS - Classifying Place of Death in Australian Mortality Statistics, published 2021

- Around two thirds of Australian die 75-95 years of age
- Estimated 70% of all deaths are expected
- Numbers of Australians who die each year will double in the next 18 years

The Grattan Report *Dying Well 2014 &* AIHW National Mortality Database 2021

So, most Australians will predictably die in very old age, probably in hospital of chronic complex illnesses.

AIHW 2022 - The last year of life: patterns in health service use and expenditure.

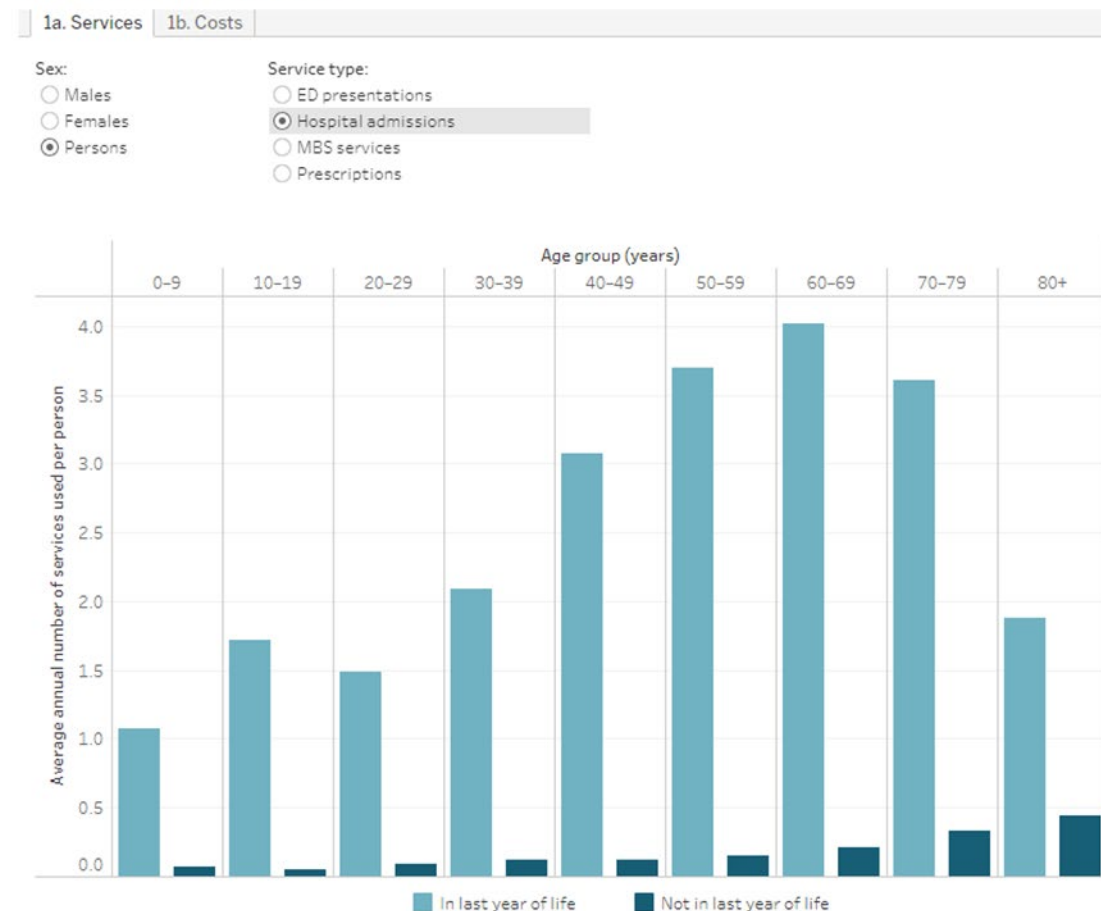Figure 1: Average annual number of health services used (a) and costs (b) per person by sex, age, service type and whether in last year of life

1a. Services | 1b. Costs

Sex:
○ Males
○ Females
⊙ Persons

Service type:
○ ED presentations
⊙ Hospital admissions
○ MBS services
○ Prescriptions

Notes:
1. Analysis for the *In last year of life* group includes services used by this group in the 12 months before their death. This includes services used between 1 July 2010 and 31 December 2016, presented as average number of services used, per person.
2. Analysis for the *Not in last year of life* group includes services used by this group between 1 July 2010 and 31 December 2016, presented as average number of services used per person over a 12-month period.

https://www.aihw.gov.au/reports/life-expectancy-deaths/the-last-year-of-life-health-service-use-patterns/contents/health-service-use-and-costs-in-the-last-year-of-l

End-of-Life Essentials

Online peer review and evidence-based education

Implementation toolkits – how to change practice

Training Resources for educators

Accreditation resources for hospitals planning on meeting the NSQHS Standards to provide a nationally consistent level of care consumers can expect from health services.

Examples of our Education Topics

Dying, a normal part of life

Patient-centred communication and shared-decision making

Recognising end of life

Goals of care

Teamwork

Responding to concerns

ED – EOLE Care

Paeds – EOLE Care

Imminent death

Chronic complex conditions – EOLE Care

States of mind at the end of life

The importance of the Patient's perspective

The drive to cure or provide intervention can overshadow the patient as a person.

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What is important at the end of life?

Talking about life & preparing for death

Thinking about who I am

Looking back & reviewing life

Understanding my legacy

Understanding time is limited

Planning how to spend the remaining time

Planning for my body after death

Forgiveness - asked and offered

Expert care

Trusting clinicians

Compassionate care

No discussion about dying or death

Reaffirming or severing social connections

Saying goodbye

Family & friends

Sharing & giving love

Effective communication

Speaking & hearing truth

ENDOFLIFEESSENTIALS.COM.AU

Steinhauser et al 2009; Virdun et al 2015; Steinhauser et al 2000; Gott et al. 2008

Patients say they wish for:

- honest communication with their health care teams

- the ability to prepare for life's end

- feeling listened to

- being aware of their physical condition

Virdun C, Luckett T, Davidson PM, Phillips J. 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 Oct: 29(9):774-96.

*We wanted to create an animation to showcase what patient's value to highlight to health care professionals.*

The animation

- Interviewed a patient with serious illness

- Thematic analysis

- Scriptwriting

- Patient review of image and script

- Process of stop motion animation with Benno Thiel at Frankie Films

- Short listed in the World Health Organisation 2024 Universal Health Coverage – Film Festival

being able to respond to
my emotion and me,
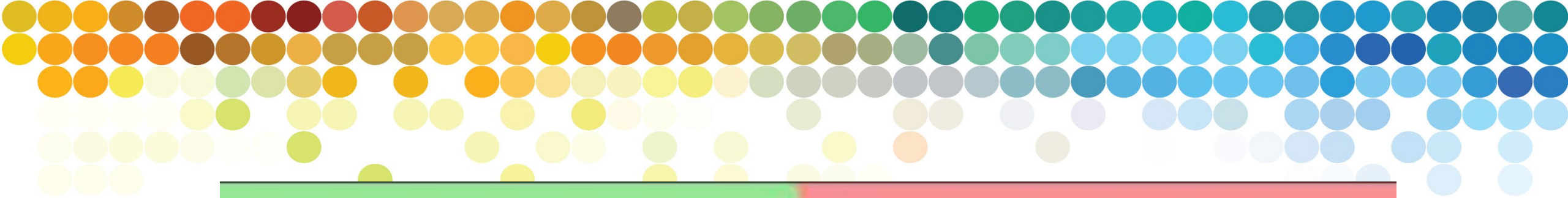
What made things worse for her, was

*not being treated like a person,

*being stripped of her identity that was *only* replaced by a diagnosis which made her feel vulnerable, lost, and unsafe.

This patient valued

- What helped her were professionals who took a few extra moments to ask about her, not about her illness, but about her as a person. To see the world through her eyes.

- How are you?

- Do you want to talk about it?

- Sounds like you've been through a lot…

- I'm so sorry things aren't better right now.

- It didn't matter so much that things weren't fixed or cured. What mattered was being seen as a person. Health professionals who can tap into these patient-centred responses can have an enormous impact on patients as people and show kindness and compassion.

Some patients will wish to know everything, other patients only some things and a smaller group will not want to know details about end of life at all - so ask.

Patients in your service and care

May ask you about your beliefs

May be very curious about their own future

May not want to discuss dying or prognosis

May want to know *everything*

Implications for practice

ABCD Care – Harvey Chochinov

Framework to enhance patient dignity. Taking a look at our own preconceived notions is a deeply personal but necessary exercise

A- Attitude - How would I be feeling in this person's situation? Am I aware how my attitudes toward the person may be affecting him or her?

B – Behaviour - Use language that the person can understand. When within hearing distance, never speak about the person's condition in terms he or she cannot understand.

C – Compassion - Compassion isn't something a person knows – it's something a person feels. It is a deep awareness of the suffering of another, coupled with the wish to relieve it. Find your role models

D – Dialogue - At this time in your life, what are the things that are most important to you, or that concern you most?

https://dignityincare.ca/en/

How to ask with . . . . .

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COMPASSION

What is your understanding of what is happening now?

What are your fears, worries and goals?

What outcomes are unacceptable/acceptable to you?

Dr. Atul Gawande, Being Mortal, 2014

End of Life Care – therapeutic humility

Demands of us an ability to manage:

Complexity – *be confronted and challenged*

Heightened emotions – *don't avoid, just be*

Uncertainty – *accept to not know the 'right' answer*

Chochinov H (2013) Health Care Provider Communication: An empirical model of therapeutic effectiveness. Cancer, May 1;119(9):1706-13. doi:

10.1002/cncr.27949.

Thank you for listening