Conversations your patients are dying to have

Dr Katherine Allsopp
Dr Sally Greenaway
Crown Princess Mary Cancer Centre, Westmead Hospital
Workshop outline

- Identify the impact of your own experience on the hospital team, patients and their families
- Who are the patients we are talking about
- What are some barriers to the conversation
- Promoting the development of conversation around treatment options
Activity
Clinical Leadership

- emotional awareness, self regulation
- passion for the work we do
- love of a challenge, persistence, commitment
- clinical excellence
- desire for improvement
The leaders role is to define reality, then give hope.

Napoleon Bonaparte
1769-1821
We must combine the toughness of a serpent and the softness of the dove, a tough mind and a tender heart

Martin Luther King Jnr (1928-68)
The Reflective Cycle

- Think of an incident and consider
- How did you feel as the event unfolded?
- How do you feel now about that critical event?
Case Mrs DM

- 85yo Advanced Vulval Squamous Cell Ca
- Tertiary referral Gynae Onc Service
- Biopsy local anaesthetic
- CT
- GynaeOnc MDT
Mrs DM

- Retired nurse
- 5 children
- Old school- Dr offers procedure
- Nursing home 100km from hospital
Mrs DM

- Symptoms - pelvic pain
- Plan for debunking excision of pelvic LN to assist with symptom control
- Pre op CNC Gynae Onc, Registrar
Mrs DM

- Proceed to theatre
- ICU
Mrs DM

- Multi organ failure
- Sepsis, inotropes, ICU discuss goals
- Discharged to ward for end of life care
Mrs DM

- Does this case ring any bells?
- How do we make good decisions in this setting?
- Did we miss opportunities to avoid non beneficial therapy?
Good Clinical Decision Making
(Remember Clinical Ethics?)
JONSEN’S FRAME WORK FOR ETHICAL CLINICAL ACTION

• HOW CAN WE HELP THESE PATIENTS AND AVOID HARM
  (beneficence and non maleficence)

• PATIENT PREFERENCES
  (autonomy vs paternalism)

• QUALITY OF LIFE (QuOL)
  (as defined and desired by the patient)

• CONTEXTUAL FEATURES
  (justice)

Gibbs’ Reflective Cycle

1. Incident
2. How did you feel?
3. What was good or bad about the experience?
4. What would you do differently now?
5. Create an action plan
6. Assess how this affected the outcome?
Mrs DM

- Lets look at the case
Empathy
Empathy

- Cognitive empathy - the ability to understand the other person's point of view
- Emotional empathy - the ability to feel what someone else is feeling
- Empathetic concern - the ability to sense what another person needs from you
- Requires trust and safety within relationships
Mrs MM

- 74yo COPD hypercapnoic resp failure 5 days
- Bipap HDU bruised face, obtunded
- Respiratory Consult 2pm Friday
- HDU nurses desperate
Who are the relevant patients?
Good Clinical Decision Making…..

Do we recognise dying any more?

How can we accurately estimate prognosis?
Clinical Frailty Scale

1. Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2. Well – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.

3. Managing Well – People whose medical problems are well controlled, but are not regularly active beyond routine walking.

4. Vulnerable – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being “slowed up”, and/or being tired during the day.

5. Mildly Frail – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6. Moderately Frail – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.

7. Severely Frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8. Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. Terminally Ill – Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common symptoms in mild dementia include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In moderate dementia, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In severe dementia, they cannot do personal care without help.


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Dalhousie University
Inspiring Minds
Barriers to End of Life Care

- Let's look at some barriers
Dana-Farber Cancer Institute, and Brigham and Women’s Hospital identify the barriers clinicians face.

The most common barriers include:
- time
- clinician uncertainty about whether they should have the conversation or leave it to a specialist
- how to select which patients should have the conversation
- inadequate documentation systems
- minimal incentives to have the conversation
Clinical disconnect

“The gap between what we do and what we know we should be doing in serious illness communication is a complex and systemic issue”

Dr Susan Block Director Palliative Medicine, Harvard
The patient with a terminal illness is asked, ‘Do you want us to do everything to help you?’
What that means to the doctor is ‘Do you want resuscitation? Do you want to go to the ICU? Do you want to go through many intensive procedures that bring with them a certain amount of suffering?’
From the patient’s point of view, who wouldn’t want us to do everything?
You need to explain the trade-offs, that extending life may mean less quality of life, sending you to a nursing home, shuttling back and forth for hospital visits.

Dr Susan Block, Director Palliative Medicine, Harvard. Forbes magazine Dec 2015
What makes a good death?
What is a good death?
To know when death is coming, and to understand what can be expected
To be able to retain control of what happens
To be afforded dignity and privacy
To have control over pain relief and other symptom control
To have choice and control over where death occurs (at home or elsewhere)
To have access to information and expertise of whatever kind is necessary
To have access to any spiritual or emotional support required
To have access to hospice care in any location including home, not only in hospital
To have control over who is present and who shares the end
To be able to issue advance directives that ensure wishes are respected
To have time to say goodbye, and control over other aspects of timing
To be able to leave when it is time to go, and not to have life prolonged pointlessly
Smith (2000)
A good death

- A good death gives people dignity, choice and support to address their physical, personal, psychological, social and spiritual needs.
A good death

- Around 70% of Australians would prefer to die at home, but only 14% actually do.

- Deaths for younger people are now rare; about two-thirds of Australians die between the ages of 75 and 95. Most of these deaths are expected, yet we are not taking the opportunity to help people plan to die well.

- Auditor General Palliative Care 2015
Few Australians die at home

Adapted from Broad et al 2013
A good death

• When asked, most people have clear preferences for the care they want at the end of their life. But rarely do we have open, systematic conversations that lead to effective Advanced Medical Planning.

• Most people do not discuss the support they would like as they die.

• It is clear that sharing our preferences for what we’d like at the end of our life is the most important – and costly conversation that Australia is not having.
Death

- In personal health care encounters, the idea that cure is improbable or impossible, or that continued life support is inappropriate or unkind, is unacceptable to many families.

- The wider problem here is that acknowledgement of the inevitability of death, and preparation for it, have largely lost their place in our culture.

- For many, an almost child-like faith in medicine and science has taken its place.

Ashby et al. 2005
Who should do the talking?
Before I Die: I want to...
Who should do the talking?

Primary care clinicians can be well suited to have conversations with seriously ill patients about their goals and values because they are trusted, long-term caregivers.

Patients often see multiple clinicians throughout the course of treatment for a serious illness, so the primary care clinicians plays a key role in ensuring patient’s care aligns with patient values.

Many barriers prevent this from occurring.

Dr. Josh Lakin, JAMA review, July 2016 “Improving Communication About Serious Illness in Primary Care.”
Who should do the talking?

- Primary health?
- Specialists?
- Acute interface doctors?
Why does it matter?

- Prognostication Study - Murphy et al NEJM 1994
  Surveyed 371 adults aged 65 or older if they wanted CPR
  - Before survival outcomes of arrest provided 41% CPR +ve
  - Given accurate arrest survival information 22% CPR +ve
  - CPR in context of life limiting illness with overall life expectancy less than 1 yr 5% CPR +ve
Overcoming the barriers

To overcome these communication barriers, Lakin concludes that primary care clinicians require, among other things:

- patient selection tools
- systems for conducting and revisiting conversations
- accessible documentation
- incentives for measurement
- feedback
- continuous improvement.

Dr. Josh Lakin, JAMA review, July 2016 “Improving Communication About Serious Illness in Primary Care.”
Overcoming the barriers
Good Clinical Decision Making …

Assessing Prognosis

many scales….
THE SPICT TOOL

The SPICT™ is a guide to identifying people at risk of deteriorating health and dying. Assess these people for unmet supportive and palliative care needs.

Look for two or more general indicators of deteriorating health.

- Performance status is poor or deteriorating (the person is in bed or a chair for 50% or more of the day); reversibility is limited.
- Dependent on others for most care needs due to physical and/or mental health problems.
- Two or more unplanned hospital admissions in the past 6 months.
- Significant weight loss (5-10%) over the past 3-6 months, and/or a low body mass index.
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).
- Patient asks for supportive and palliative care, or treatment withdrawal.

ECOG >+3

SPICT TOOL: a Haem Disease/Malignancy and 2+ score associated with Poor Px
The goal of an end-of-life conversation — ideally, multiple conversations as circumstances change — is for people to clearly state their choices.

“For me and members of my family, we want to know what we’re getting into and don’t want unnecessary pain and suffering.”

As these conversations between doctors and patients become routine, it will reduce Medicare dollars mounting in last months of life. That’s because more people will make the kinds of informed choices that doctors make for themselves today.

Earl Blumenauer. Rep congress. Affordable Care Act (Obamacare) USA
What we need to talk about

1. What is your understanding of where you are and of your illness?
2. Your fears or worries for the future
3. Your goals and priorities
4. What outcomes are unacceptable to you? What are you willing to sacrifice and not?
And later,
5. What would a good day look like?

Asking these allows everybody to understand what the goal really is.

Atul Gawande, Being Mortal
CONVERSATIONS
Creating Choice in End of Life Care
When it comes to death the statistics are clear. We will all die.

WHAT
It’s time to transform our culture so we shift from not talking about dying to talking about it. It’s time to share the way we want to live at the end of our lives. And it’s time to communicate about the kind of care we want and don’t want for ourselves and our loved ones.

WHAT
1. Currently, too many Australians experience pain and suffering in the final months and days of their lives, and die in a way they would not choose. These outcomes ripple out beyond the dying person to their families, loved ones, caregivers, and communities.
2. As a nation we are paying a high price for care we don’t want, in a place we don’t want it.
3. Caring for the dying is a fundamental responsibility of all societies and good stewardship of national resources requires an evidence-based approach to meet the ever-increasing and insupportable demands on hospital facilities, health professionals and ineffective resource utilisation.

HOW
The pathway to reform starts with one simple step – conversation.
Conversations increase public awareness that End of Life Care can be guided in ways that responded to patients’ choice. When it comes to End of Life Care, one conversation can make all the difference.
Death and Dying:
How we respond to it has changed

The “Medical Model” – that is dealing with a “Delinquent Body”- prevails
thank you