

# Challenging conversations at the end of life

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October 2018



# Outline

- Background context
- Evidence regarding communication
- What you and your patient bring to the interaction
- Truth-telling, prognosis and hope
- An approach to communication



*‘The good physician treats the disease; the great physician treats the patient who has the disease’* (Shorter 2001, citing Osler)

# CONTEXT




# Professional-patient interaction

- The central act of healthcare is when one *‘human being turns to another human being for help’* (Gawande 2014)
- This fundamental unit of healthcare, the professional–patient interaction, is not an equal partnership
  - Poor communication further disempowers the patient.
- There are no special techniques for conversations about the end of life beyond the approach to difficult conversations in general
  - But end of life conversations may be remembered for years and in turn colour the end of life experiences of those who were involved.



# Attitude

- *“There is nothing you can do that will make bad news better, but there is plenty you can do to avoid making bad news worse.”*
- Manner, attitude and skill of communication are important.
- But we start from a low base: the “hello my name is” campaign.

# **hello** my name is...  




# Errors in communication

- These are usually much less about being trained in advanced communication skills and more about a failure to apply the basics of good communication skills.



# ON BETTER COMMUNICATION



*“The single biggest problem in communication is the illusion that it has taken place” (George Bernard Shaw)*

# EVIDENCE





# Literature

Both patients and clinicians are affected by the quality of the exchange during consultations.

Effective communication has been associated with:

- Improved psychological functioning of the patient, adherence to treatment & pain control, enhanced information recall and higher quality of life & satisfaction.

Ineffective communication contributes to:

- Clinician stress, lack of job satisfaction and emotional burnout .
- Patients' confusion, increased psychological distress and difficulty in asking questions, expressing feelings & understanding information.

(Ford S et al. *Soc Sci Med* 1996; Lerman C et al. *Cancer* 1993; Razavi D et al. *Psychooncology* 2000; Loge JH et al. *Eur J Cancer* 1997; Fallowfield L. *Br J Cancer* 1995; Lamont EB et al. *Ann Intern Med* 2001; Maguire P et al. *Eur J Cancer* 1996)



# Literature

Most patients with advanced, life-limiting illness have high information needs concerning prognosis and life expectancy.

(Hancock K et al. *Palliative Medicine* 2007)

Professionals present fewer facts and less detail concerning prognostic information compared to other types of information.

(Miyaji N et al. *Social Science & Medicine* 1993)

“*The truth may hurt, but deceit hurts more*”: well-intentioned withholding of information may be detrimental for patients, family and professionals in the long term.

(Fallowfield L et al. *Palliative Medicine* 2002)



# Literature

Poor communication skills with patients by physicians are the main cause of medical disputes and are linked with malpractice litigation

(Adamson D et al. *Western Journal of Medicine* 1989; Levinson W et al. *JAMA* 1997; Hamasaki T et al. *BMC Family Practice* 2008)

The patient's perception of care (e.g. a perceived lack of concern on the part of the treating team) has a marked impact on their subsequent decision to commence litigation or lodge complaints

(Messenger O. *Canadian Family Physician* 1989; Rodriguez H. *International Journal for Quality in Health Care* 2008)



# Communication skills training

Communication skills do not reliably improve with experience

(Cantwell BM et al. *Medical Education* 1997)

Communication skills training:

- Is effective at improving some types of healthcare professional communication skills related to information gathering and supportive skills (e.g. use of open questions, showing empathy)
- Shows no improvement in healthcare professional “burnout”, patient physical or mental health, or patient satisfaction.

(Moore PM et al. *Cochrane Database of Systematic Reviews* 2013)



# A STARTING POINT



# ***WHAT YOU BRING***



# You may:

- Lack time.
- Be flustered or caught by surprise
  - Have a standard approach for this.
- Worry about the emotional response/getting shouted at.
- Worry about opening a ‘can of worms’.
- Worry about causing offence e.g. appearing to ignore cultural values.
- Worry about taking away hope.



# Personal attributes

These may be innate or learned:

- A non-judgmental approach.
- Empathy.
- The capacity for curiosity.
- Self-awareness on the part of the professional and the capacity for self-critique.





# Communication skills

There are multiple communication skills of differing sophistication, but the starting point is to get the basics right.

- Having adequate time.
- Use introductions.
- No unexplained jargon.
- “Turning up” to the conversation.
- Active listening.
- Use of summarising/checking meaning.
- Acknowledge emotion: *Say what you see.*



# Communication skills

- Normalise the emotion rather than the experience.
- Be aware of stoicism.
- Sensitivity to the problems of sensory or cognitive impairment.
- Sensitivity to the deference to authority shown by some people to those in healthcare.
- Avoidance of one's own blocking behaviours:
  - Frequently interrupting the person; Being distracted during the conversation; Being overly task-orientated; Disregarding emotional cues.



*‘This world is above all a practical and moral one in which patients have life projects and everyday concerns, things “at stake”’ (Mattingly 1998)*

## ***WHAT THEY BRING***



# The patient (family) may:

Bring a story to tell

- You will only have a degree of understanding of their experiences, so best to avoid saying “I understand”, even if you share a similar experience.

Seek understanding (meaning) and support

- Meaning may be “created” through stories.

Repeat their story to you a number of times

- Have you heard the emotion?

Not start from a neutral position in their interpretation of your language and body language.

Want you to solve problems, or may not

- Avoid undermining their experience.



# Phases of Acting-Out Behavior



(Colvin and Sugai, 1989)

## Patient/Relative

- |                  |   |
|------------------|---|
| 1. Calm          | Engages in conversation and decision making.          |
| 2. Trigger       | Experiences a series of unresolved conflicts.         |
| 3. Agitation     | Increased in unfocused behaviour.                     |
| 4. Acceleration  | Focused behaviour.                                    |
| 5. Peak          | Out of Control.                                       |
| 6. De-Escalation | Having vented the severity of the behaviour subsides. |
| 7. Recovery      | Attempts to correct problem.                          |



# Cognitive biases

- A cognitive bias is a pattern of deviation in judgment that occurs in particular situations.

(Haselton M et al. (2005). *The evolution of cognitive bias*. In Buss (Ed.), *The Handbook of Evolutionary Psychology*, 2005)



# Some common cognitive biases

*(You have these, too)*

## Affective forecasting errors (projection bias)

- Difficulty projecting yourself into the future.

## The default option

- This is often for more aggressive care.

## Optimism bias

- Tendency to discount future benefits so as to avoid present pains.

## Present-biased preferences

- The issues that patients consider most pressing tend to be those arising from direct experience.



# ***THINGS TO CONSIDER***





# Truth-telling

Systematic review of 46 studies relating to truth-telling in discussing prognosis with patients with progressive, advanced. Life-limiting illness and their care-givers.

- Most HPs believed that patients/care-givers should be told the truth.
- In practice, many avoided the discussion or withheld information.
- Reasons: lack of training; lack of time to respond to emotional needs; fear of negative impact; uncertainty about prognosis; requests by family to withhold information; feeling inadequate or hopeless.

(Hancock K et al. *Palliative Medicine* 2007)



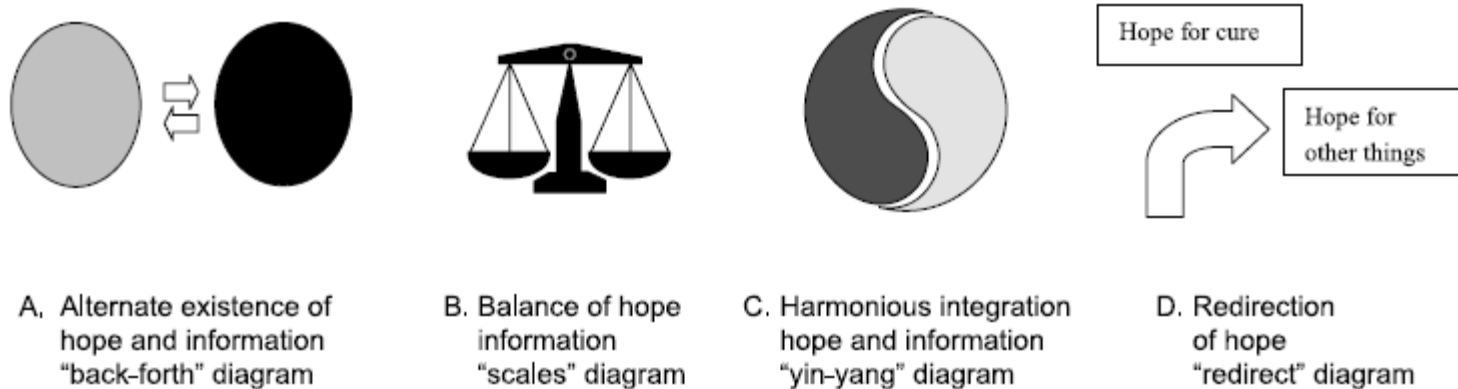
# Hope v prognosis

A qualitative study of 55 patients (with advanced cancer or COPD), 36 family members, 31 doctors and 25 nurses looked at four approaches to communication about prognosis.

- Hope is an important response to a life-limiting diagnosis.
- The value is therapeutic hope is well established.
- In two of the approaches, information is viewed as a threat to hope: we should provide prognostic information cautiously and indirectly
- In the other two approaches, information is not viewed as compromising hope and more direct information giving may be used.

(Curtis J et al. *Journal of Palliative Medicine* 2008)





**FIG. 1.** Potential four diagram conceptual model for the process of hope and prognostic information that may be helpful for clinicians caring for patients with terminal or life-limiting disease.

- A: Use an approach that alternates between hopefulness and acknowledgement.
- B: Use an approach that maintains a balance between maintaining hope and acknowledging a poor prognosis.
- C: Allows the holding of hope and prognosis together, neither one precludes the other.
- D: Allows a redirection of hope for a cure to hope for something else e.g. quality of life.

# Content, style and timing of information

Systematic review (by the same group), again of 46 studies, showed that:

- Patients/caregivers have high levels of information need at all stages of illness, regarding the illness itself, likely future symptoms and their management, life expectancy, clinical options.
- Information needs tend to diverge as illness progresses: caregivers needing more and patients wanting less information over time.
- Preference for a health professional who shows empathy, honesty, encourages questions and actively clarifies each individual's level of understanding and information needs
- Most people want at least some discussion of these topics at time of diagnosis or shortly after, but want to negotiate content and context.

(Parker S et al. *Journal of Pain and Symptom Management* 2007)



# Triggers to a conversation (Mullick A et al. *BMJ*, 2013)

## Include

- Patient initiates the conversation.
- Diagnosis of a progressive life limiting illness.
- The diagnosis of a condition with a predictable trajectory, which is likely to result in a loss of capacity, such as dementia or motor neurone disease.
- A change or deterioration in condition.
- Change in a patient's personal circumstances, such as moving into a care home or loss of a family member.
- Routine clinical review of the patient, such as clinic appointments or home visits.
- When the previously agreed review interval elapses.



# Initiating the conversation (Mullick A et al. *BMJ*, 2013)

## Examples:

- How have you been coping with your illness recently?
- Do you like to think about or plan for the future?
- When you think of the future, what do you hope for? (Pantilat S et al. *JAMA*, 2004)
- When you think about the future, what worries you the most? (Pantilat S et al. *JAMA*, 2004)
- Have you given any thought to what kinds of treatment you would want (and not want) if you became unable to speak for yourself? (Quill T. *JAMA*, 2000)
- What do you consider your quality of life to be like now? (Quill T. *JAMA*, 2000)



# High and low assumption communication

## ‘High assumption’ communication:

- Meaning is often “compressed” through the use of metaphor and jargon.
- This is an efficient method of information delivery where there is a high degree of shared assumptions and understandings.

## ‘Low assumption’ communication:

- Implies a need for more clarity of explanation because of fewer shared assumptions.

## Healthcare:

- Has a mixture of the two contexts (professional-professional and professional-patient interactions) and communication styles should not adapted accordingly.
- Use of a high assumption communication style in a low assumption context can lead to misunderstandings.



*'Man is not destroyed by suffering; he is destroyed by suffering without meaning'* (Victor Frankl, 1984)

# A PRACTICAL APPROACH





# A practical approach

1. Preparation
2. Openers
3. Establishing communication preferences
4. SCIP: Story, Context, Issues, Plan



# 1. Preparation

- Gather as much information as you can beforehand, if this is possible. People find it reassuring to know that you have done this.
- Involve other staff as appropriate (and hand over to colleagues afterwards).
- Think about:
  - Environment (privacy, light, noise)
  - Which colleagues to have with you
  - Room set-up
  - Avoidance of interruptions



## 2. Openers

- Remember that challenging conversations are often an attempt to find meaning in the context of suffering.
- So choose your opening words with care; at their best these can establish a focus on the person, not just on the problems.
- On meeting the patient/family (ideally when for the first time) gain important information about the *kind of person* the patient is.
  - This helps to establish a therapeutic and trusting relationship (by proxy if necessary).



## 2. Openers

- For example:
  - “What do I need to know about you as a person to best help me help you?”
  - “Give me three bullet points to describe your character.”
- This ‘gold dust’ information helps you to see the person in their own context and may prove useful in tailoring treatment to the individual.



## 3. Establish communication preferences

- This will save you a lot of time later on and help prevent communication mistakes:
  - “Are you the sort of person who likes to know all the details of what is happening to you, or do you just want the headlines?”
  - “Who would you like with you when we are having important conversations?”
  - “Are you happy for us to discuss your care with your family eg on the phone?”
- If done at the outset these questions don’t carry any “bad news baggage”.



## 4. SCIP: *Story, Context, Issues, Plan*

Establish understanding:

- What the patient/family knows (*story*).
  - This allows you to pitch the conversation at the right place.
  - Sometimes not all family members know everything.
  - Revisit communication preferences if appropriate.
- The goal of care, if this is not obvious (*context*).
  - Has this changed?
  - How does the goal of care alter what we do?

What does the patient/family want to discuss, what do you want to discuss (*issues*)?

(Noble B et al. *BMJ Support Palliat Care* 2014)



## 4. SCIP: *Story, Context, Issues, Plan*

Watch and listen for clues about how the conversation is being received.

- Be prepared to stop.
- Acknowledge the impact of uncertainty.
- Discuss your *plan* and gain consent.
- Summarise.
- Record.

(Noble B et al. *BMJ Support Palliat Care* 2014)



# Conclusions

Professionals and patients/families alike are challenged by some forms of communication.

Everyone is affected by the quality of communication.

No one size fits all, so a sensitive approach that allows the clinician to tailor communication is needed. This need not be complicated.

Avoiding simple errors of communication goes a very long way in improving the standard of the challenging conversations we have on a daily basis.

