

Challenging conversations at the end of life

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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?

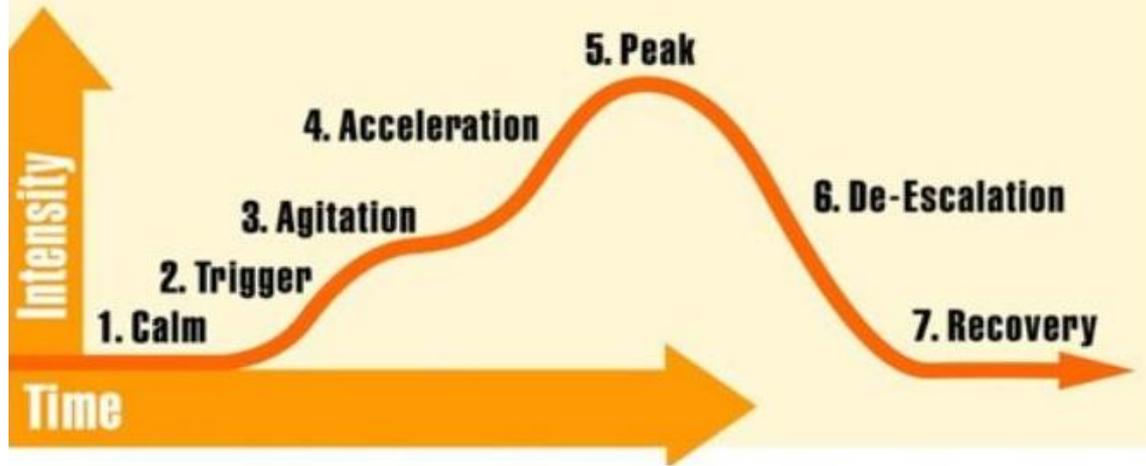
Not start from a neutral position in their interpretation of your language and body language.

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)



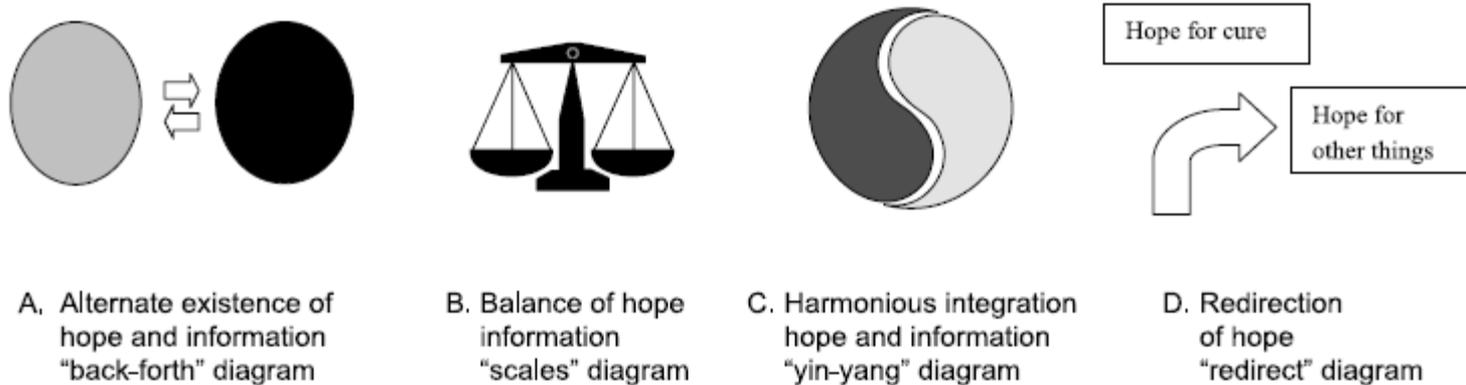


FIG. 1. Potential four diagram conceptual model for the process of hope and prognostic information that may be helpful for clinicians caring for patients with terminal or life-limiting disease.

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.

