Real Talk

Engaging patients in end of life talk.

Who goes first? Compassionate routes toward discussing patient's illness progression and death with them

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How do experienced doctors and patients do something that is often very difficult: starting up discussions about the patient's prognosis and death?

In Western healthcare, most people agree that those with life-limiting conditions should have opportunities to discuss their prognosis and preferences for end-of-life care well before it becomes difficult for them to engage in meaningful conversations. Surveys tell us that patients, carers, and professionals see communication about dying as important yet very difficult to do. The difficulty is worth teasing out. Death is so sensitive and potentially distressing that patients and relatives are often reluctant to raise it with professionals. Therefore, it might seem appropriate for healthcare professionals themselves to be first to raise it. However, even raising it can cause real distress and harm to some patients in some circumstances. Also, professionals are often worried that talking about end-of-life might take away hope, and might make things worse. So here is the question:
How can professionals navigate the dilemma of minimising harm whilst also giving people opportunities to discuss prognosis, dying, and end of life care?

Methods

To find out, we studied how experienced doctors promote conversations about dying with their patients. We recorded consultations between experienced palliative medicine doctors and patients with life-limiting conditions, including those where a spouse, relative or friend accompanied the patient. Altogether, we recorded 37 patients and 17 companions with 5 doctors in a large English Hospice. We used a research approach called 'conversation analysis'. This allowed us to describe in detail some strategies that experienced doctors use to initiate conversations about dying.

Findings

We found that doctors neither wait for patients to 'go first' in raising dying, nor ask patients to do so. Instead, they take a cautious, elegant, and often step-by step approach towards the topic. Specifically, they often invite patients to expand on something they themselves had already raised. We term these invitations 'Elaboration Solicitations'. In Elaboration Solicitations (or Invitations), doctors encourage patients to elaborate on something they have already said. We found that they started off cautiously, and if the patient did not open up an end of life topic, the doctors pushed a little harder. The most cautious approach we call

Fishing questions

These invitations from doctors are fashioned to give patients an opportunity to raise dying in response if they chose to do so, but they do not force the issue. That is, doctors' invitations don't actually suggest or propose end of life as a topic for the conversation. Patients sometimes respond by volunteering concerns or thoughts about the end of their lives, but sometimes they don't. The invitations are worded so that it is perfectly possible for the patient to respond about other matters without having to directly refuse to talk about the end of their life. For instance, when a patient has reported a problem such as pain, shortness of breath, or low mood, the doctor invites them to say more.

Here's an example:

"And when the pain's bad and you start to feel a bit panicky, can you remember what's going through your mind at that time?"

We found that in cases where patients didn't volunteer end-of-life matters, doctors sometimes try again – sometimes straight away, sometimes later in the consultation. At this point, the doctors increasingly narrow the focus to encourage patients to respond in terms of end of life matters. One way they did so was to use what we call

You said paraphrases

In these, the doctor picks up on something the patient said, and asked them about this in such a way as to push towards – though not explicitly name – an end of life matter

For example:

"So just going back to you worrying about your back pain, are you able to share what's worrying you most at the moment?"

"So coming back to what you were saying before for a second Lynn, part of it is the fear of what might happen?"

The experienced doctors we studied repeatedly gave patients opportunities to be the first to introduce dying into the conversation. It was much less common to introduce it on the patient's behalf.

Proffering a possible end of life thought on the patient's behalf

In some consultations doctors choose to ask about the patients' thoughts about dying rather more directly – for instance: "Do you worry about what's coming?". This puts the patient in the position of needing to confirm or deny.

Whilst the doctors prioritise giving opportunities to the patients to volunteer talk about dying, they also use this strategy flexibly: using their judgment to decide when it was appropriate to more explicitly encourage the patient to talk about dying. On the next page, we give a diagram of the doctors' step by step approach.

We are getting this research out into the world of healthcare by using it in a communication training package called 'Real Talk'. Real Talk includes clips from the video-recordings we made at the hospice, alongside learning exercises and evidence summaries. Real Talk is being used to train healthcare staff and trainees in NHS hospitals, and in hospices and universities. We are also beginning video-based research on the communication challenges and skills entailed in specialist palliative physiotherapy and occupational therapy.

Information:

For more information go to our website www.realtalktraining.co.uk or follow us on twitter @RealTalk_EOLC

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