Encouraging and discouraging talk about future illness, dying and death: a systematic review

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Background and aims

Communicating with patients and others about their feelings and preferences for the future is an important but challenging element of care.

There is useful evidence from studies within linguistic and social scientific fields, but these are rarely recognised and accessed by practitioners, educators, and policy makers. We aimed to systematically review and synthesise evidence about communication practices from social scientific research involving study of audio or video recorded conversations about future illness, dying and death. The purpose was to inform policy, practice and training, to aid those responsible for talking with patients about future illness and care.

Methods

We adapted established systematic review methods to allow search and handling of social science, clinical and linguistics research. Two of the inclusion criteria were: analytic reliance on naturalistic audio or video recordings, and English language data. We searched electronic databases and specialist sources, and conducted systematic data extraction and synthesis.

Results

2026 publications were initially identified. Of the 19 meeting the inclusion criteria, 8 were social science, 6 linguistics and 5 clinical publications. Key practices documented are:

'Fishing' questions

Ask a question that 'fishes' for talk about the future. e.g. 'Can I just ask you, what are your greatest concerns Liz?'

(4/19 publications). Usually fail to elicit talk about the future. **Allusive, vague comments and statements** e.g. 'Have you heard of hospices?' 'I'm concerned that, you know, things might not go so well for you.'

(5/19 publications). Offers easy opportunities to deflect or avoid the topic.

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Framing the future as a general concern

e.g. 'One of the things that we know we're sort of faced with sometimes when people get very ill is views about post-mortems in general and I just would like to know what you feel about them in general.' (2/19). This encourages talk by somewhat insulating the topic from patient's reality.

Posing hypothetical questions

Pose a hypothetical situation then ask a question about it e.g. Say, we can't say and you can't say, but say you did begin to get ill, or say you got so ill that you couldn't kind of make decisions for yourself, who would you...'. 'Just supposing, this is all hypothetical, but I would just like to know'

(10/19). These are often employed after initial fishing questions and allusive talk. Very frequently succeed in eliciting 'on topic' answers – make it difficult to deflect or avoid the topic.

Steering to more optimistic statements e.g. `It's potentially serious but the majority of these are cured.'

(4/19) People habitually steer towards the positive. The person responding generally follows, thus closing off further talk about difficult matters.

Conclusions

• Practices vary in how forcefully they encourage talk about the future. Recognising and understanding practices and their consequences can help clinicians tailor their communication to individual circumstances

- Studies in linguistics and sociology usefully document ways of enacting difficult clinical tasks such as encouraging people to talk about death
- Each practice has an array of advantages and disadvantages
- Maintaining hope by expressing optimism is clearly important, but clinicians may want to delay such moves in some circumstances because this closes off talk about future difficulties and associated plans
- There is an evidence gap about how these topics are discussed once raised, including ways of progressing to talk about advance care plans

