In a Nutshell Series



Engaging patients in end of life talk.

Encouraging and discouraging talk about future illness, dying and death

Ruth Parry, Victoria Land and Jane Seymour bit.ly/ParrySystReviewCommAboutFuture

Communicating with patients and others about their feelings and preferences for the future is important in many care contexts, but it is also challenging. There is useful evidence about how best to communicate about these matters in the fields of linguistics and social science. But this evidence is rarely accessed by practitioners, educators and policy makers. We systematically reviewed evidence about communication from research in which social scientists and linguists have made and analysed video and audio recorded conversations about future illness, dying and death.

Methods

We adapted established systematic review methods to allow handling of social scientific, linguistics and clinical research on communication practices. We only included research which relied on video or audio recorded conversations in English (and specifically conversations and consultations that would have happened whether or not research was being done). We searched electronic databases and specialist sources. We extracted and aggregated our data systematically.

Findings

2887 publications were initially identified; 19 met our inclusion criteria: 4 were social science publications, 8 language and social interaction, and 7 were clinical publications. The key communication practices documented in this literature are:

Fishing Questions (5/19 publications)

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

These are gentle and cautious, don't force answers, but often fail to elicit talk about the future

Indirectness, allusive talk, and euphemisms (6/19 publications)

'Have you heard of hospices?'

'I'm concerned that, you know, things might not go as well for you'

In a Nutshell Series

Offers a gentle knock on the door, but with easy opportunities to deflect or avoid the topic, in response, patients sometimes 'open the door' to difficult topics

Hypothetical questions (12/19 publications)

Pose a hypothetical situation then ask a question about it:

'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...'

Often employed after initial fishing questions and allusive talk. These very frequently succeed in eliciting on-topic answers – because you are talking hypothetically, it is more difficult for the conversational partner to deflect or avoid the topic.

Linking questions or proposals to what the patient has said/not said (7/19 publications)

'What Michael mentioned initially is that...he didn't have any concerns but he's been feeling funny again is that a worry?'

This both shows you have been paying attention to what has been said, and it works to selectively focus conversations towards difficult future topics

Framing a difficult issue as a universal or general (4/19 publications)

'One of the things that we know we're sort of faced with sometimes when people get very ill is views about [organ donation] in general, and I just would like to know what you feel about them in general'

This way of talking about the difficult issue can facilitate engagement with that issue because it somewhat insulates the difficult topic from patient's personal reality.

Features other than words that convey sensitivity (4/19 publications)

Hesitant talk, touch

These features of communication enable you to convey that you recognise the personal sensitivity of what is being talked about

Features other than words to encourage patient talk once topic has been broached (2/19 publications)

Leaving gaps of silence, continuers such as 'Mm', 'OK'.

Sometimes not talking, or not saying much is a powerful way of encouraging further talk about difficult issues.

Conclusions

Direct, observational research on real life conversations has highlighted a number of ways people engage in talk about difficult future issues. These vary in how forcefully they encourage talk about the future: there are pros and cons to the more cautious / gentle and the more forceful ways of encouraging talk about difficult topics. Recognising and understanding these can help practitioners tailor their communication to individual circumstances. There are evidence gaps, including: what very expert practitioners do, the role of touch and both body movements, and how these topics are discussed once raised – including ways of progressing to talk about advance care plans.

In a Nutshell Series

Information:

<u>r.parry@lboro.ac.uk</u> @CACEnotes <u>RealTalk@lboro.ac.uk</u> @RealTalk_EOLC <u>www.realtalktraining.co.uk</u>

Acknowledgements to:

Loughborough University, University of Nottingham, LOROS Hospice Leicester, The Health Foundation and the NIHR. The views expressed in this publication are those of the authors and not necessarily those of the NHS, the National Institute for Health Research, Health Education England or the Department of Health and Social Care.