

Talking about dying

How doctors and patients talk about life expectancy

When patients have life-limiting conditions, doctors need to talk with them about dying. These conversations can be difficult for doctors, patients, and patients' family members. Professor Ruth Parry and Dr Marco Pino, from Loughborough University, analyse recordings of conversations during which patients request life expectancy estimates. They then use the findings from this research to develop training resources that can help clinicians to create, with their patients, conversational environments that support sensitive and honest communication about how long a patient has to live.

Sometimes in healthcare, difficult conversations are unavoidable. When caring for patients with life-limiting conditions, talking about dying is an inevitable component of care for patients and their families. Discussing future illness progression and life expectancy can enable patients to make plans for their future and to communicate their concerns about and preferences for end-of-life care. However, these conversations present doctors, patients and their families with dilemmas. While doctors have a duty to inform patients of how their condition might impact their future, they may be reluctant to do so for several reasons. They may fear destroying patients' hope. They may want to protect them from the emotional harm that can result from hearing such information. They may also fear the consequences should their prognostic estimate turn out to be incorrect. Patients face dilemmas of their own: whilst they are entitled to ask about prognosis, they may be uncertain about how much they can and should ask. They may dread hearing a gloomy prognosis. They may also be uncertain about their doctors' ability and willingness to estimate their life expectancy.

Ongoing research aims to investigate how patients and experienced doctors, patients, and accompanying family members interact in order to understand how these difficult conversations go. Subsequently, this knowledge can be used to help clinicians reflect on and improve their own interpersonal skills, and thereby enhance their practice.

CONVERSATION ANALYSIS

The vast majority of research on how doctors and patients with life-limiting illnesses interact has relied on written or spoken recollections and opinions from staff, patients and carers. This is an indirect way to study interactions. Directly observing and analysing recordings of real-life interactions provides far richer, more nuanced knowledge and insights.

The approach that Professor Parry, Dr Pino and their colleagues use is named conversation analysis. This approach allows detailed examination of how people design their talk, providing information about the words they use and – crucially – precisely how they deliver them. Conversation analysis provides a way to identify and describe components of our communication that usually go unnoticed. Just as anatomists provide valuable knowledge about the inner workings of the human body, so conversation analysts provide knowledge about the inner workings of human communication. Conversation analysts can provide explicit descriptions of those parts of our communication which, even though they are absolutely vital to how we understand one another, normally go unnoticed as we go about our social lives. This is why analysing recordings of real-life interactions provides detailed understandings that go beyond (and sometimes even contradict) what is available through individuals' recollections and reports.



In the majority of cases, patients requested life expectancy estimates after the doctor provided an opportunity to influence the consultation agenda.

The rigorous approach of conversation analysis can be used to study not only how people interact with others in everyday life, but also in specialised settings including health and social care. In this context, it can be used by researchers of healthcare communication to identify practical problems and dilemmas that doctors and patients face within their interactions, as well as the strategies they use to navigate those problems and dilemmas.

ANALYSING LIFE EXPECTANCY TALK

Using recordings of real-life consultations, Professor Parry and Dr Pino directly examine how patients and doctors – and also patients' family members – navigate the dilemmas of talking about dying in their face-to-face interactions. One of the areas they have focused on is how and when patients request life expectancy estimates, that is, seek information on how long they are likely to live, or how long it might be before they die.

Their study of life expectancy estimates was based on ten recordings of consultations during which the topic of life expectancy came up. These consultations took place in a large UK Hospice. The doctors were experienced palliative medicine specialists and the patients had been told they had a life-limiting condition. They analysed patients' estimate requests and doctors'

initial responses. More specifically, they looked at whether patients made estimate requests at particular junctures within the consultations, how they made them, and what doctors and patients' family members did following patients' requests.

THE TIMING OF ESTIMATE REQUESTS

The study showed that patients did not just randomly raise the matter of life expectancy, but did so in particular places within consultations. Most commonly (in seven of the ten cases studied) the patient raised it straight after the doctor had provided an opportunity for the patient or companion to steer the conversation. For instance, the doctor offered an opportunity with a simple question such as "Anything you'd like to ask me?" Alternatively, the doctor gave their patient a nudge by asking a question that more clearly pointed towards end-of-life related concerns, for example: "Do you worry about what's coming?" or by the suggestion that future appointments and conversations could entail talking about the future.

Although Professor Parry and Dr Pino found that the most common way in which patients raised the topic of life expectancy was to wait for the doctor to provide them with an opportunity to steer the conversation, some patients proceeded differently: in the remaining three cases

the patient requested an estimate after talk about scan results, prognosis, or place of death.

HOW PATIENTS DESIGN THEIR REQUESTS

It is known that when we make requests of one another, the way we word those requests provides two important pieces of information about what we are assuming about our request. Firstly, our wording conveys whether we assume that granting the request will be easy or difficult. Secondly, our wording conveys whether we assume ourselves to be more or less entitled to make that request. For instance, if we word our request as a question such as "Can you do X?" we convey that we anticipate that it will be fairly straightforward and easy to grant our request, and we portray ourselves as entitled to make this request. Whereas by wording our request not with a question, but with a statement such as "I wonder if X," we show that we anticipate there might be difficulties granting our request, and also that we recognise that we may not be fully entitled to make that request.

The research team drew on these understandings to analyse how patients design life expectancy requests. They observed that the three patients who did not wait for a doctor-provided opportunity to request an estimate did so by posing direct questions such as "How long have I got?" However, they observed that in the seven other cases, rather than posing such direct questions, patients cautiously displayed their interest in receiving an estimate by using statement formats, for example "I'm worried I'm not going to last as long as they thought I would." or "I feel I'm waiting for the Grim Reaper, but I don't know when he's coming." Through using statement formats like these, patients convey low entitlement to request an estimate, and that they anticipate the doctor might have difficulty in providing it. Furthermore, because the patient doesn't overtly ask for an estimate, they leave it for the doctor to infer that this is indeed a request. By requesting in this cautious way, patients can avoid coming over as pressuring the doctor to provide information they might be unable or unwilling to provide. What we see in practice is that doctors do indeed opt to treat this kind of statement as a request for a life expectancy estimate. We know from

research in other contexts that when one person makes a comment about a topic on which the person they're talking to is knowledgeable, then the knowledgeable person treats this comment as a request for information. When patients make statements that convey some gap in their knowledge about life expectancy, this pattern comes into play: the doctor, as the person knowledgeable about medical matters, treats the statement as a request for a life expectancy estimate.

TUNING IN TO PATIENTS

Professor Parry and Dr Pino also found that often when patients cautiously raise the matter of life expectancy, alongside this, they volunteer quite a bit of relevant information. They volunteer what they already know (or not) about: their prognosis e.g. "I asked the prognosis initially, and it was about a year"; their perspective and feelings on it: "I don't mind, cos I know I'm dying"; their readiness and reasons for wanting prognostic information e.g. "don't be squeamish, I wanna know... I've got a few things I want to do"; and their understanding that giving a precise estimate is difficult e.g. "I know you can't say how much time I've got left".

By giving doctors this information, patients provide them with insights into their state of mind in relation to their life expectancy. By sharing their readiness, what they already know, and their perceptions and feelings, patients help to prepare the ground. That is, they help build conversational environments in which doctors can deliver estimates in ways that are sensitive to and designed for this particular patient, at this particular time in their journey.

Sometimes though, patients do not, or only partially, share this information alongside their initial requests. When that happens, doctors cautiously work their way, step by step, to collect the missing information and make sure the patient is ready to hear an estimate. By doing so, the doctor works out, with the patient (and sometimes their family member too), whether this really is the right time for giving an estimate. At this point, the doctor sometimes withholds a life expectancy estimate and proposes, for example, that they discuss the prognosis in a future appointment. The patient, doctor, and



Rather than posing direct questions such as "How long have I got?", patients cautiously displayed their interest in receiving an estimate.



patient's family member thus cooperate, working together in preparing a favourable conversational environment in which patients' emotional states, readiness, and uncertainties are addressed before a life expectancy estimate is delivered.

IMPLICATIONS FOR CLINICIANS

Findings from conversation analytic research can be used in communication training and can help clinicians with the difficult conversations they may have with patients. On the basis of their data and their findings, Professor Parry and Dr Pino have, with their team, built training resources which are available online at the Real Talk Initiative's website (www.realtalktraining.co.uk). Some of these are publicly available, others are available (upon application) to NHS, Hospice, and

University-based trainers who provide communication training to NHS staff and trainees. There are also materials for overseas trainers.

The training resources teach clinicians how to design questions that help patients to articulate what they know about their prognosis, how they feel about it, and whether they are ready to hear more. The resources highlight that clinicians should be alert to the fact that patients sometimes raise life expectancy indirectly by cautiously communicating their interest in receiving estimates, rather than by overtly asking some version of "How long have I got?" Clinicians can also learn some communicative practices to help prepare conversational environments that are favourable to the delivery of estimates.

Behind the Research



Dr Ruth Parry



Dr Marco Pino

E: r.parry@lboro.ac.uk T: +44 07960602675 W: <https://www.realtalktraining.co.uk/> @CACENotes @RealTalk_EOL

Detail

Brockington Building
Loughborough University, Epinal way
Loughborough, LE11 3TU. UK

Bio

Ruth Parry worked for several years as an NHS Physiotherapist before moving into research. Her interests include how people explain things to one another, and how they navigate conversations that people tend to find difficult, sensitive, and distressing. She is keen to make the valuable findings of research on language and social interaction more accessible to healthcare practitioners and educators.

Marco Pino is a lecturer at Loughborough University. He studies interpersonal communication in palliative

care, bereavement support, and clinical treatment for drug misuse. His interests include how healthcare providers and clients discuss sensitive and difficult topics, and how they manage conflicts and disagreements.

Funding

This project was supported by the Health Foundation (Grant references: GIFTS 7210, AIMS 1273743, AIMS 1273316), an independent charity committed to bringing about better health and health care for people in the UK. In addition, Ruth Parry receives funding from the National Institute for Health Research Academy Career Development Fellowship ("Enhancing staff-patient communication in palliative and end of

life care" Grant Reference CDF-2014-07-046). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

Collaborators

The doctors, patients, and patients' family members who allowed us to record their conversations.

LOROS Hospice Care for Leicester, Leicestershire, and Rutland. The Centre for Research in Communication and Culture, Loughborough University.



References

- Pino M. & Parry R. (2019). Talking about death and dying: Findings and insights from five conversation analytic studies. *Patient Education and Counseling*, 102(2), 185–187. <https://doi.org/10.1016/j.pec.2019.01.011>
- Pino M. & Parry R. (2019). How and when do patients request life expectancy estimates? Evidence from hospice medical consultations and insights for practice. *Patient Education and Counseling*, 102(2), 223–237. <https://doi.org/10.1016/j.pec.2018.03.026>
- Parry R., Whittaker B., Pino M., Land V., Jenkins L., Faull C., Feathers L., Watson S. (2020). Facilitator Manual. Real Talk. Available at: <https://www.realtalktraining.co.uk/app/uploads/2019/12/Real-Talk-Manual-Jan-2020.pdf>
- Parry R. & Pino M. (2019). Preparing the ground - how do patients and doctors communicate about remaining life expectancy? Real Talk. Available at: <https://www.realtalktraining.co.uk/app/uploads/2019/11/Preparing-the-ground-how-do-patients-and-doctors-communicate-about-remaining-life-expectancy-.pdf>

Personal Response

Now that you've analysed how patients request life expectancy estimates, what will you look at next?

Our analysis highlights why it makes sense to talk about sensitive topics in quite indirect, equivocal ways. Patients do so to avoid pressuring doctors and also to carefully suss out if this doctor is willing to talk about prognosis with them. Doctors tread carefully so as to work out the patient's knowledge and perspective and emotional state, thereby working out whether their patient is currently in the right place to hear life expectancy information. So, there are good reasons to talk in ways that are indirect and equivocal. Nevertheless, there are drawbacks. Sometimes doctors and patients end up spending considerable time and effort working out whether the patient does or does not want to talk about, and hear more about, the sensitive topic. Doctors face a conundrum: how to clarify what a patient wants whilst continuing to tread carefully. We are currently examining different strategies doctors use in the face of this problem, and hope that by doing so, we can help doctors decide which strategies to use and when.