# Talking about death and dying: findings and insights from five conversation analytic studies

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This special section of Patient Education and Counseling is dedicated to advancing knowledge on communication about the end of life in healthcare settings. The five studies in the special section use the theoretical tenets and the analytic techniques of conversation analysis (CA). In this editorial we briefly overview prior CA research on communication about death and dying, we illustrate how the studies in this special section advance this research, and we consider the potential of CA studies to contribute further to understandings of this area of social life.

## **Conversation analysis**

CA is a rigorous approach to the study of how people interact with others through language and other communicative resources both in everyday social life and in specialised settings, including health and social care. CA allows researchers of healthcare communication to identify practical problems and dilemmas that healthcare practitioners and patients face within their interactions in a variety of clinical settings; as well as the communicative practices they use to navigate those problems and dilemmas. CA researchers analyse recordings of real-life interactions, yielding detailed understandings that go beyond (and sometimes even contradict) what is available through individuals' recollection and reporting of communication problems and practices.

Two aspects of CA are especially relevant for the topics of this special section. The first relates to CA's origins in sociology, and consists of a particular perspective on people's social interactions (1). Rather than addressing social problems or debates in broad and abstract terms or with *a priori* assumptions about people's motivations and understandings, researchers using CA start their investigations in a highly empirical manner, focusing on observable conduct within recorded interactions. Through this particular lens, CA studies identify ways in which

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people's actions reflect their understandings of broader problems, dilemmas and debates in society. The studies in this special section examine the ways in which healthcare practitioners, patients and their families manage some of the dilemmas associated with communication about death and dying in their real-life interactions. In this way, these studies contribute to wider debates regarding social practices and communication about death and dying.

A second aspect of CA that is especially relevant to the focus of this special section is its attention to detail. Researchers using CA examine how people design their talk to manage particular problems in their interactions. Using this approach, the studies in this special section examine the ways in which healthcare practitioners, patients and their families engage in communication about the end of life. Their findings contribute, among other things, to current debates regarding whether or not healthcare practitioners should use the words 'death' and 'dying' rather than more euphemistic or allusive alternatives.

### Communication about death and dying

Prior research has suggested that communication about death and dying shares some features of communication about personal troubles (2). Research on informal conversations about personal troubles has shown how this type of talk is socially constrained. For example, people do not simply discuss their troubles at any point in a conversation. Rather, they use specific communicative actions to build a conversational environment that is conducive to the articulation and sympathetic reception of a trouble (3). For example, people generally do not introduce their troubles abruptly into conversations; instead, they work their way towards them (4), or they give clues that there might be a trouble and then report it when their interlocutor asks about it (5). Exiting troubles talk is also socially constrained and involves a series of stepwise moves (6). This body of research shows that troubles talk requires favourable conversational environments; environments where troubles can be safely shared and appropriately understood.

Prior research on healthcare communication suggests that favourable conversational environments are also required to raise death and dying. People put special care into approaching the topic, maintaining it as a focus in the conversation, and exiting it. Pioneering work by Peräkylä on HIV/AIDS counselling (examining counselling sessions recorded in the 1980's when HIV positivity was by and large a terminal diagnosis) shows that counsellors employ a stepwise questioning strategy to create favourable conversational environments for clients to voice their thoughts and fears about dying (7). This strategy also gives patients the opportunity to volunteer their concerns about dying whilst avoiding explicitly inviting them to do so. Subsequent research on oncology consultations (8), hospice medical consultations (9), paediatric palliative care consultations (10), and psychotherapy sessions with cancer patients (11) shows that medical doctors and psychotherapists (at least in some settings) employ similar stepwise questioning strategies. These practices help healthcare practitioners navigate a central dilemma: how to promote talk about death and dying whilst avoiding explicitly or overtly inviting patients to do something that they might be reluctant to do and that might trigger great distress.

## The special section

The study by Shaw and colleagues in this special section further extends the line of inquiry summarised above by examining a particular questioning practice ('meaning expansion enquiries') in CALM psychotherapy sessions (12). Shaw and colleagues focus on that element of CALM psychotherapy which involves helping the terminally ill patient to entertain alternative perspectives on the benefits and risks of pursuing or declining further treatment. They point out that in helping the patient to engage with alternative perspectives, therapists need to navigate at least two dilemmas: the potential invalidation of the patient's already displayed perspective, and the possibility of triggering distress by acknowledging the shortness of remaining lifespan (and what could or should be done in it). The therapist's meaning expansion enquiries invite the patient to elaborate on what they have already indicated about their own perspective. This initiates a stepwise sequence wherein the therapist subtly indicates there could be an alternative perspective to that which the patient has voiced, and wherein both parties collaboratively build a favourable conversational environment for articulating and engaging with that alternative perspective.

The study by Ekberg and colleagues contributes to debates about the explicitness or implicitness of end-of-life talk (13); for example, whether practitioners should engage patients and their relatives in talk about the end of life by explicitly using the words "death" and "dying" (14). In several ways, the studies summarised above (on stepwise questioning strategies) already show that patients and their families can and do accomplish conversations about end of life without necessarily referring to death and dying in so many words. Stepwise questioning strategies offer patients opportunities to engage in talk about death and dying without explicitly inviting such talk (although sometimes practitioners subtly cue patients to the possibility of doing so (9)). The issue is that inviting someone to talk about something obliges them to overtly accept or reject this invitation; healthcare practitioners often avoid putting patients and their relatives in this potentially delicate position (9). Ekberg and colleagues examine paediatric palliative care consultations and demonstrate that family members and clinicians refer to a child's prospect of dying without using the words "death" and "dying". Rather, they rely on other communicative resources (including the context and design of the talk). A key finding is that the implicit ways of introducing death and dying are taken by the people involved as unequivocally invoking death and dying. Although further research is needed to define the circumstances in which using inexplicit communicative practices (e.g., terms such as "it" and "that"; euphemisms; and allusions) does or does not give rise to ambiguities for patients and their relatives (8), Ekberg and colleagues' research demonstrates that explicitly using the words "death" and dying" is not essential for accomplishing frank conversations about a patient's end of life.

Gill's paper is the first to examine talk about death in surgical consultations for early-stage breast cancer (15). Focusing on a consultation involving a patient with early-stage breast cancer and a surgeon, Gill shows that the surgeon explicitly refers to the possibility that the cancer could spread to vital organs and kill the patient. The surgeon does so in order to dispel possible misconceptions about breast cancer and to inform the patient about the importance of treating node-negative breast cancer with chemotherapy. Tate has similarly found that oncologists use direct terms (e.g. "deadly", "dying") when encouraging uptake of a particular

treatment (16). These findings point to another important aspect of communication about end of life: whether the prospect of dying is explicitly or implicitly invoked in a conversation seems to depend—at least in part—on what the participants are trying to accomplish. That is, when they are trying to promote a conversation focusing on the end of life, more implicit and cautious communicative practices are used; when pursuing some other project—in Gill's study, uptake of treatment—practitioners more explicitly invoke dying. Ekberg and colleagues' study also supports this conclusion. In their study, family members and clinicians used explicit references to death and dying at points in the conversation when the focus was upon the death of someone other than the family's own child.

Cortez and colleagues focus on cases where talk about end of life does not emerge—or only rarely. In earlier work on oncology consultations that include the communication of scan results the research group found that "oncologists spend the shortest amount of time on the discussion of scan news and its prognostic implications" (17). Oncologists move the conversation from scan results to talk about treatment by using communicative practices that invite patients to appreciate how treatment has prolonged their life (18). These practices can bypass opportunities to engage in talk about the implications of scan results for patients' understandings about their prognosis. Cortez and colleagues' paper here further extends this line of study by examining another communicative practice (the 'exhausted current treatment' statement) that can bypass discussion of scan results and their implications, and initiate discussion of further treatment options instead (19). Rapid transitions between talk about scan results and talk about treatment options may reduce opportunity spaces for patients and their caregivers to enquire about the prognosis (17).

Pino and Parry's paper examines hospice medical consultations. It describes how patients and doctors create favourable conversational environments for patients' requests, and doctors' estimates, about life expectancy (20). Predominantly, the primary focus of research discussed in this editorial has been on healthcare practitioners' actions that promote (or limit) talk about end of life. By contrast, Pino and Parry's primary focus is upon patients' communicative practices (for previous studies on patients' communicative practices, see 21, 22). Pino and Parry find that rather than asking some form of 'How long have I got?' question, patients cautiously display their interest in receiving an estimate of life expectancy by using statements. Pino and Parry also find that within their statements, patients—and their companions—often provide preparatory information. This preparatory information concerns what they already know about their prognosis, how they feel about it, and their readiness to know more. When patients do not convey these matters, doctors invite them before giving an estimate. This means that when estimates are delivered, emotional states and uncertainties have already been acknowledged and considered (and indeed, in one of the cases this establishes the patient is *not* ready to know—and the doctor does not go on to give an estimate).

#### **Contribution and Conclusion**

This special section showcases the empirically-grounded, highly detailed evidence that conversation analytic research can contribute to understanding how people communicate about end of life. Clearly, gaining access to and recording actual conversations about end of life for conversation analytic work entails practical and ethical challenges (23), but the researchers

contributing to this special section demonstrate it is both possible and worthwhile. In their seminal paper, Peräkylä and Vehviläinen discuss how conversation analytic studies can contribute to understandings and guidance on communication by adding detail and specificity; and/or by falsifying or correcting assumptions (24). Each of the studies here adds detail and specificity to our understandings of how people communicate about death and dying and why they do (or do not) do so in particular ways. For instance, Cortez and colleagues' findings add detail to understandings of oncology consultations and of opportunity spaces for end of life talk, whilst Shaw and colleagues add specificity to knowledge about communication strategies for psychotherapeutic interventions. Some of the studies (Ekberg and colleagues, Pino and Parry) challenge a prevalent assumption that (only) by referencing death and dying explicitly can we ensure all parties understand that end of life is being talked about. Relatedly, Gill's study challenges an associated assumption: that within healthcare interactions, practitioners generally treat death as a delicate, even taboo, topic. In combination, their findings indicate we need more nuance in debates and understandings of how we do and how we should talk about death and dving. These studies show that in their real-life interactions, highly experienced patients and highly experienced practitioners sometimes refer to death very explicitly, whilst at other times they do so with highly sensitive, cautious, indirectness (whilst nevertheless making it evident that each of them understands that what is being addressed is the patient's death). Conversation analysts take it that people communicate as they do for good reasons. That is, they take it that particular communication practices get used because they work to navigate particular dilemmas. The papers in this special section show us that there are contexts where there is good reason to refer to end of life directly and explicitly, but other contexts where there is good reason to be highly indirect, tentative, and cautious. At the start of this editorial, we noted that conversation analytic studies address broader problems, dilemmas and debates in society by examining observable evidence about these matters within social members' (recorded) conduct. The papers in this section demonstrate, but by no means exhaust, the ways in which conversation analytic work can inform, develop, and challenge social problems, dilemmas and debates about death and dying.

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