

# BMJ Open 'Conditional candour' and 'knowing me': an interpretive description study on patient preferences for physician behaviours during end-of-life communication

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## ABSTRACT

**Objective:** To understand patients' preferences for physician behaviours during end-of-life communication.

**Methods:** We used interpretive description methods to analyse data from semistructured, one-on-one interviews with patients admitted to general medical wards at three Canadian tertiary care hospitals. Study recruitment took place from October 2012 to August 2013. We used a purposive, maximum variation sampling approach to recruit hospitalised patients aged ≥55 years with a high risk of mortality within 6–12 months, and with different combinations of the following demographic variables: race (Caucasian vs non-Caucasian), gender and diagnosis (cancer vs non-cancer).

**Results:** A total of 16 participants were recruited, most of whom (69%) were women and 70% had a non-cancer diagnosis. Two major concepts regarding helpful physician behaviour during end-of-life conversations emerged: (1) 'knowing me', which reflects the importance of acknowledging the influence of family roles and life history on values and priorities expressed during end-of-life communication, and (2) 'conditional candour', which describes a process of information exchange that includes an assessment of patients' readiness, being invited to the conversation, and sensitive delivery of information.

**Conclusions:** Our findings suggest that patients prefer a nuanced approach to truth telling when having end-of-life discussions with their physician. This may have important implications for clinical practice and end-of-life communication training initiatives.

## INTRODUCTION

Seriously ill patients have identified a physician's skilful communication as a priority in end-of-life (EOL) care.<sup>1</sup> There is currently no standard definition of EOL communication, but prior work has focused on how advance care planning (ie, anticipatory planning for future personal and healthcare

## Strengths and limitations of this study

- Data obtained are directly from seriously ill patients about their preferences for physician behaviours during end-of-life communication.
- The findings provide practical recommendations for improving patient–physician end-of-life communication that can be used in communication training for physicians or used as part of a complex intervention study.
- Although the qualitative sampling strategy attempted to include non-Caucasians, we were able to recruit only Caucasians to the study.
- We recruited participants with both malignant and non-malignant disease from three tertiary academic hospitals but findings may be different in community hospitals or in outpatient settings.
- The theme 'conditional candour' is a novel finding that describes a nuanced approach to truth-telling.

decisions in the context of one's values) can facilitate more immediate 'in the moment' decision-making about treatment preferences in the context of a serious illness.<sup>2</sup> For the purposes of this study, EOL communication can be understood as a broad concept that includes advance care planning, in-the-moment decision-making about discrete treatment choices and related information-sharing processes, such as prognostic disclosure. Previous studies have suggested that some of the greatest opportunities for improvement in EOL care pertain to physicians' roles in communication processes, including information-sharing, listening and involving patients in the decision-making process.<sup>3–5</sup> Despite these studies, less is known about patient perspectives and preferences with respect to physician behaviours during EOL



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communication. The objective of this qualitative study is to understand patient perspectives on physician behaviours during EOL communication. The results are intended to provide practical knowledge and insights that can be incorporated into a physician's clinical practice. In addition, the results could inform communication skills training initiatives for physicians and trainees.

## METHODS

In this multicentre qualitative study, we recruited inpatients from three Canadian academic tertiary hospitals in Hamilton, Ontario and Calgary, Alberta. Recruitment occurred from October 2012 to August 2013.

This qualitative study was part of a mixed methods study involving the collection of quantitative and qualitative data to examine seriously ill patients' perspectives on physician behaviours during EOL communication. The quantitative data will be published elsewhere.

We first recruited patients to the quantitative strand (cross-sectional survey using a structured questionnaire) of the mixed methods study using inclusion criteria that identify a population of seriously ill medical inpatients aged 55 years or older with an estimated 6–12-month mortality risk of 50% (see [box 1](#)), similar to criteria used in previously published studies.<sup>4 5</sup> Patients were excluded from the quantitative strand if they were cognitively impaired (dementia or delirium as documented in health records, or healthcare team or research nurse

assessment), unable to speak or read English, or were too fatigued or sick to participate. In addition, patients were also excluded if they could not recall any previous EOL communication encounters with a physician, or if they were admitted for less than 48 h. Hospital charts were reviewed to assess eligibility, and a research nurse approached the healthcare team and potential participants to further assess eligibility for recruiting to the study. A total of 152 patients met the eligibility criteria and were approached to participate in the quantitative strand. A total of 132 patients consented, resulting in a response rate of 86.8%.

We used a maximum variation sampling technique<sup>6</sup> to invite a subset of the survey participants to participate in semistructured, qualitative interviews. Our sampling strategy aimed to recruit a study sample with different combinations of the following demographic variables: race (Caucasian vs non-Caucasian), gender and diagnosis (cancer vs non-cancer). This strategy is supported by the literature, which suggests that Caucasians and females are more likely to participate in EOL communication processes.<sup>7 8</sup> In addition, there is evidence to suggest that the uncertain prognoses associated with non-cancer illnesses, as compared with cancer illnesses, pose a barrier to EOL communication.<sup>9</sup> After a verbal and written consent process, all participants provided informed consent to participate in the study.

We chose to conduct an interpretive description study because this method allows for the generation of knowledge that is relevant to healthcare disciplines.<sup>10</sup> In keeping with the epistemological stance of interpretive description methods, data collection and analysis were conducted through the lens of a physician (AA-R), with a focus on information that would be pertinent to other front-line physicians.<sup>11</sup> Data saturation was not a desired outcome, as Thorne states, "patients theoretically represent infinite variation in relation to their experiences with health care."<sup>12</sup> Instead, the focus was on obtaining a deeper understanding of the patient perspective while still recognising that outliers may exist.

We collected data from patients' charts regarding age, gender and primary diagnosis and asked patients directly about educational and ethnic background. Qualitative data were collected during one-on-one, in-person interviews that ranged from 22 to 78 min duration.

One of the authors (AA-R) conducted all the interviews to ensure consistency in approach. Initially, the interview guide included only one open-ended question asking participants to share any relevant EOL communication experiences with a physician, after explanation of EOL communication was given and any questions were answered. The development of the interview schedule was an iterative process, and additional questions were added based on concepts derived from previous interviews (see [box 2](#) for sample interview questions). When participants could only recall experiences of a family member rather than their own experience, this was also allowed as it was felt to be helpful in gaining insight into

### Box 1 Inclusion criteria for qualitative study on seriously ill hospitalised patients' perspectives on physician behaviours during end-of-life communication

Age  $\geq 55$  years and at least one of the following:

- A. Hospital admission for congestive heart failure with New York Heart Association (NYHA) Class IV symptoms or left ventricular ejection fraction  $\leq 25\%$ .
- B. Hospital admission for severe chronic obstructive pulmonary disease with one or more of the following: body mass index  $< 21 \text{ kg/m}^2$ ; an exacerbation requiring hospitalization over the past year; shortness of breath causing the patient to stop walking after 100 m or after a few minutes on level ground; forced expiratory volume in 1 s ( $\text{FEV}_1$ )  $\leq 30\%$  predicted or partial pressure of carbon dioxide ( $\text{PaCO}_2$ )  $\geq 45$  torr.
- C. Hospital admission for liver cirrhosis with at least one of the following: history of hepatic coma; Child's class C liver disease or Child's class B liver disease with gastrointestinal bleeding.
- D. Hospital admission for issue related to active metastatic cancer.
- E. Any medical inpatient  $\geq 80$  years of age.
- F. Any medical inpatient for whom a physician answers 'no' to the following 'surprise' question: "Would you be surprised if this patient died within the next year?"\*

\*The 'surprise question' has been evaluated in prospective studies involving cancer, dialysis and primary care patients, and shown to be effective in identifying patients with an increased risk of mortality in 1 year.<sup>30</sup>

## Box 2 Sample interview schedule

**Introduction:** This research study will be looking at how doctors' behaviours can be helpful or not in discussing your future healthcare needs. We are especially interested in topics such as planning what kind of medical care you would want in the future if you cannot speak for yourself; who would like to speak on your behalf if you could not speak for yourself. We are also interested in conversations about issues such as whether or not you would like certain medical interventions.

**Initial question:** Can you tell me about your experience with discussing these issues or related topics with doctors in the hospital?

**Emerging questions:** Can you tell me about a conversation with a physician that went badly?

Can you tell me about a conversation with a physician that went well?

Who should start the conversation about your health outlook and your personal decisions about your future healthcare? (ie, yourself, your family or the doctor?)

What is the right time for the doctor to talk about what to expect for your health and future decision-making?

future EOL communication preferences. Interviews were audio-recorded and transcribed verbatim. Field notes were taken to capture observations made during the interviews that would later help to contextualise data during analysis.

We used a constant comparative approach, in which new data were compared to emerging themes from previous interviews to allow for further understanding of concepts and refinement of themes.<sup>10 13 14</sup> In addition, data collection and analysis occurred in a concurrent and iterative fashion: the interview schedule underwent two cycles of modification during the data collection process, as emerging themes led to the addition of new question probes. To enhance the validity of results, all transcripts were read individually by each of two authors (AA-R and DS) and then consensus was reached on the categorisation of data into themes, based on literal and interpretive meanings. Key categories were compared to identify similarities and were then organised into major themes and subthemes. Through the use of the 'thoughtful clinician test',<sup>10 15</sup> evolving interpretations were shared with an internal medicine physician (JY) with clinical experience in EOL communication in order to receive feedback about the congruence of the findings with his clinical encounters with seriously ill hospitalised patients. As another validation strategy, we discussed developing themes and conceptualisations, derived from previous interviews, with participants in order to assess whether these aligned with their personal views—a form of 'member checking'.<sup>10</sup>

## RESULTS

We interviewed 16 patients, most of whom were women (69%) and 70% had a non-cancer diagnosis. Despite the use of a maximum variation sampling strategy with an

aim to recruit both Caucasian and non-Caucasian participants, we were only able to recruit Caucasian participants (see [table 1](#)).

Analysis of the interview transcripts led to the identification of two major themes. The first major theme, 'knowing me', relates to the influence of life history and social relationships on shaping personal values and preferences for healthcare. This theme is further subdivided into the subthemes 'acknowledging family roles' and 'respecting one's background'. The second major theme, 'conditional candour', describes a preference for receiving frank information from a physician, but with some important qualifications, which are elaborated in the subthemes 'assessing readiness', 'being invited to the conversation' and 'appropriate delivery of information'.

## Knowing me

### Acknowledging family roles

Participants expressed appreciation for a physician who actively engaged family members during EOL conversations. Some participants explained that family members are deeply invested in their EOL decision-making because they were expected to take on the role of

**Table 1** Participant characteristics (n=16) in qualitative study on seriously ill hospitalised patients' perspectives on physician behaviours during end-of-life communication

Characteristic	Number of participants (%)
Gender	
Male	5 (31)
Female	11 (69)
Age (years)	
55–59	1 (6)
60–69	4 (25)
70–79	2 (13)
80–89	6 (38)
>89	3 (19)
Ethnicity	
Caucasian	12 (100)
Non-Caucasian	0 (0)
Education level	
Elementary school	2 (13)
High school diploma	8 (50)
Postsecondary school (university or college)	5 (31)
Missing	1 (6)
Primary diagnosis	
Cancer	
Breast	2 (13)
Colorectal	2 (13)
Oropharyngeal	1 (6)
Non-cancer	
Chronic obstructive pulmonary disease	3 (19)
Congestive heart failure	2 (13)
Medical inpatient >80 years old	6 (38)

surrogate decision-maker. By including family in EOL conversations, they can be informed of the patient's wishes, thereby alleviating some of the future burden associated with substitute decision-making:

I've already spoken to [son] about decisions, and, you know, resuscitation. He has to understand where I'm coming from and I want him to be involved in it...I don't want him being lost, you know, with not knowing, not having had that conversation. So we had it and he's okay with it. (Participant 7: female, age range 60–69 years old)

When participants spoke of scenarios in which a seriously ill family member was the focus of EOL communication, the importance of involving family seemed to take on a slightly different rationale. In such situations, family members were perceived to provide important emotional or psychological support to the individual, as expressed by the same participant who made the previous statement:

When my mom was really sick we all went there [the hospital] and the doctor kind of sat and looked around the table and said, 'There's too many people here.' They wanted to take her into a room and tell her she had cancer...by herself. And I said, 'You know what? We're all coming. You're just going to have to deal with it, because you're going to tell her, you're going to get up and you're going to leave the room and we're going to be left with the aftermath.' (Participant 7: female, age range 60–69 years old, non-cancer diagnosis)

In effect, participants conveyed that they were part of a close network of loved ones, and it was important for the physician to engage in decision-making with the family, in addition to the patient. From the patient perspective, involving family seemed to allow loved ones to stay informed of their clinical status and helped them to share their future healthcare decision-making preferences, thus potentially lessening the future burden of surrogate decision-making. From the perspective of being a family member of a seriously ill individual, participants endorsed a need to provide support during a difficult encounter.

### Respecting one's background

When giving examples of physicians who communicated well, respondents pointed to those who took an active interest in their personal life. Over the years, such physicians accumulated knowledge of the milestones, trials and triumphs experienced by their patients:

Well it's because they know you, they know what you're like and, you know, it's just like the doctor that saw [my daughter] learning to drive. I mean you could see the fun he got out of thinking 'I brought her into the world and now look, she's driving a car.'...It's not self-pride, it's like a family. It's a continuation. (Participant 13: female, age range 80–89 years old)

Participants endorsed that this sense of familiarity has implications for improving EOL communication, as highlighted by these two data excerpts:

Well there's sort of a bond or connection between you. If you know someone fairly well it's easier to do things with them, work out plans. But if you're more like a stranger, um they really don't know what you might like or what's best for you and you don't really understand them. (Participant 16: female, age range 70–79, cancer diagnosis)

**Participant:** I don't know about this [new] doctor but Dr. [name], he knew the whole family. He knew everything about us...I'd been a patient for so long that he practically knew everything about me, you know. So I think the longer you go to a doctor I think the more relationship there is between the two of you.

**Interviewer:** So that rapport, how do you think that rapport would affect your talking about these advance care planning issues?

**Participant:** I'd be more open and I think he would be too because he'd be more comfortable, you know. (Participant 4: female, age range >80 years old, non-cancer diagnosis)

As has been made evident by the above examples, participants frequently conveyed that the sense of personal connectedness they share with a physician they have known for a longer period of time helps to facilitate high-quality EOL communication. These physicians were more likely to understand their patient's values and personal definitions of quality of life, and thus could tailor discussions to their individualistic needs. Furthermore, participants often expressed a more psychological benefit of knowing their physician, whereby a sense of familiarity promoted trust and seemed to instil a sense of confidence.

### Conditional candour

Participants expressed a desire for candid communication from the physician about issues such as health status, expected trajectory of illness and prognosis. The following quote is an example of a typical way in which satisfactory encounters were described:

He [doctor] was very open and very clear about what he was telling me. He didn't sort of hide away from it or pull punches. (Participant 5: male, age range >80 years old, cancer diagnosis)

Candid information-sharing was felt to have both practical and emotional implications. Participants consistently explained that disclosure of information allowed for informed healthcare decision-making, personal planning and helped to preserve autonomy:

How can you make decisions about what you want if you don't have all of the information you need? If he says

'You've got six weeks' and you think 'Maybe there are ends I haven't wrapped up yet.' Nobody wants to leave things unfinished....even if they just wanted to say good-bye to certain people. (Participant 9: female, age range 60–69 years old, non-cancer diagnosis)

However, the successful delivery of candid information appeared to be contingent on certain factors, as discussed in the following subthemes.

### Assessing readiness

The data suggest that sharing information when people are not mentally prepared to receive it may be harmful to the patient's emotional welfare and potentially the patient–physician relationship:

I think right from the start, the first interview I had [with oncologist] they said, 'We can't cure you. We can just help make things better.' One of the reasons I didn't like that statement is because I think they take all hope, all your wishes and they're just washed down the drain... (Participant 16: female, age range 70–79 years old, cancer diagnosis)

It sometimes proved to be much more challenging to engage in effective EOL conversations when a patient was not ready to consider the gravity of their illness. In such situations, despite a physician's strident efforts to discuss EOL matters such as goals for future healthcare, the conversations were not fruitful. This was made evident during an interview with a participant with advanced chronic obstructive pulmonary disease (COPD):

Despite having been recently extubated and discharged from the ICU, a female with advanced COPD felt that there was no need to engage in EOL conversations because she did not believe that her illness was advanced. With further discussion it became evident that her physician had in fact communicated the advanced nature of her disease and the difficulty of weaning off intubation should she need it in the future. When mentioning this conversation with her physician, she did so as though it was of little significance. She reasoned that if intubation worked once, it should work again, and she expected to heal with time. (Participant 9: female, age 60–69 years old, non-cancer diagnosis)

### Being invited to the conversation

At times, it may be difficult for a physician to confidently evaluate a patient's readiness to engage in EOL conversations. In fact, participants had insight into the potential challenges that physicians may face in trying to assess readiness:

I guess the [doctor] has to feel around for how much information do I want and then go about, uh, then she has to determine how it's to be presented to me. So you know, very difficult questions to resolve. (Participant 15: male, age range 60–69 years old, cancer diagnosis)

Given the challenges, some participants suggested that it may be preferable and more practical to obtain direct permission from the patient:

Just lay it out there and say there's some stuff that showed up on your test or whatever that I'd like to discuss with you if you want to discuss it. And if you're serious about not knowing then we don't have to discuss it. (Participant 14: female, age range 55–59 years old, cancer diagnosis)

Thus, some participants suggest a simple strategy to help physicians deal with the challenges of assessing patient readiness to engage in EOL communication. This may be even more helpful in situations where there is less familiarity between a patient and physician and patient communication preferences are less likely to be known.

### Appropriate delivery of information

Participants expressed that the desire for candid information does not obviate the need for a sensitive approach to communication:

This one doctor came up who was head of that department and this is the difference in human beings. He came up and he says 'it's about time you realized your wife is dying.'...That is no way to speak. (Participant 8: male, age range >80 years old, non-cancer diagnosis)

Despite the consistently expressed belief in the right to receive clear information about their health status and prognosis, participants specified that it should be framed in a way that conveys compassion and acknowledges the distressing emotions that arise from such conversations. Candid information can be provided in such a way that it is not blunt or callous, allowing for clear understanding while maintaining compassion in the delivery.

In addition to appropriate style of delivery, a related finding is the importance of considering the context in which EOL-related information is delivered. Respondents felt that it was important to consider factors such as the physical environment, timing and privacy:

A female came through the door and kind of woke me up, yelled 'I need an answer yes or no.' And I said, 'I'm sorry, I'm just not in a position right now to make a decision.' And she said, 'well I have to know, yes or no.' (Participant 11: female, age range 80–89 years old, non-cancer diagnosis)

Well you know, something that is really, really impersonal is the head honcho doctor swooping into your room followed by 15 interns all with their notepads out all asking questions. (Participant 15: male, age range 60–69 years old, cancer diagnosis)

A recurrent theme related to the need to immediately follow prognostic information with discussions about future options for care. It is inferred that physicians who discussed future care plans were able to preserve a patient's hope while 'breaking bad news'. Sometimes this hope centred on a cure or for a prolonged lifespan, while in other cases it related to preserving quality of life or achieving a good death:

If a doctor honestly believes that I am so far advanced in an illness that I couldn't possibly live very much longer, then I would appreciate him saying to me, 'Well, it looks as though we've come to the end of the road but I'll make you as comfortable as possible, make your going out as good as I can.' (Participant 8: male, age range >80 years old, non-cancer diagnosis)

## DISCUSSION

In this qualitative study of seriously ill hospitalised patients' perspectives on EOL communication with physicians, we identified two types of physician behaviours that were felt to be beneficial. The first, entitled 'knowing me', involves attentiveness to a person's background, social and family roles. The second relates to patient preferences for frank communication, but with some important stipulations. This theme, entitled 'conditional candour', involves an evaluation of a patient's readiness to engage in EOL conversations, being invited to the conversation, and attentiveness to contextual factors, such as appropriate timing and sensitive language. We acknowledge that other perspectives may exist and that what has been presented here does not represent an exhaustive list of patient preferences. However, our findings provide knowledge that can be used to help align EOL communication strategies with some patient preferences as suggested by the data.

Physicians who can recognise that each patient has had a rich life journey may be more likely to communicate in a manner that conveys respect, humility and a commitment to an individualised approach to EOL communication. Our study suggests that in some cases family members' opinions can have a strong influence on EOL decisions, and failure to include them in the conversation, when desired by the patient, may lead to less fruitful discussions. The importance, and active involvement, of family members in EOL conversations and decision-making is echoed in studies of elderly patients, those with metastatic breast cancer, end-stage renal disease and congestive heart failure.<sup>16–19</sup> It may be inferred that in some circumstances, it is more helpful to view the 'patient' as a group of people: the individual with the illness and the loved ones who form their support network. Recent qualitative work in which physicians were asked about their perspectives on family involvement during the transition to palliative care provides complementary knowledge: physicians valued the presence of family members as they were perceived as being best able to provide emotional support for the patient,

yet interestingly physicians largely viewed a family member as being unhelpful when their perspectives did not align with that of the physician.<sup>20</sup> Further support of the need to include family members as part of the 'patient unit' is provided by the Inter-professional Shared Decision Making (IP-SDM) model,<sup>21</sup> which recognises family members as key participants in the decision-making process. In our study, participants suggested that it was important to include family in EOL discussions because it allowed them to prepare for their anticipated responsibility as surrogate decision-makers and thus reduce the burden of decision-making in the future. In this way, our findings contribute to the current body of literature by providing a plausible explanation for the importance of involving family members in the EOL communication process from the patient perspective.

There was a clear preference from patients for candour about EOL-related topics with their physician, because it allowed patients to plan for the future and to say goodbye to loved ones. Other studies in cancer, renal disease and congestive heart failure populations also provide evidence of patient preferences for candid EOL communication,<sup>22–24</sup> including a discrete choice experiment on chronic kidney disease patients, which found that most wanted early and detailed provision of prognostic information and other EOL communication topics.<sup>25</sup>

A novel finding in our study is the concept of 'conditional candour', which provides a unique insight into the conditions in which a candid exchange of information can thrive. A physician who can *assess a patient's readiness* to engage in EOL communication is more likely to have a fruitful discussion and avoid invoking emotional distress. This finding is supported by another qualitative study, which put forth the idea that physicians should learn how to appropriately 'titrate information'.<sup>23</sup> By actively seeking an *invitation*, the physician has an opportunity to confirm readiness, and it gives the patient a chance to refuse and/or possibly defer to a loved one. A sensitive approach to the *delivery of information* about diagnosis, prognosis or other EOL-related topics, and attention to environmental and contextual factors is necessary to avoid worsening the trauma that may be experienced during such difficult times. In our study, it appeared that hope could be focused not only on life prolongation, but also on preserving quality of life or achieving a good death, and a physician's ability to follow the delivery of difficult news with forward-looking options for care was interpreted as helping to maintain hope. The findings within the theme 'conditional candour' are supported by previously published work on 'breaking bad news' in which the authors suggest that physicians ask patients how they would like to receive information, and to preserve hope by discussing future plans for care, such as symptom control.<sup>26</sup> Furthermore, in a qualitative study on patients with metastatic cancer and former family caregivers of

deceased patients with cancer, participants noted the vulnerable position of being told that no further chemotherapy was available, and wanted physicians to guide patients on how to focus on living after chemotherapy, such as by focusing on activities that were missed because of frequent clinic appointments or enjoying time with family.<sup>27</sup> The idea of the multifaceted nature of hope, including hope for cure, survival, comfort and dignity, has been emphasised in previously published work.<sup>28 29</sup>

The main strength of our study is the substantive nature of the findings described above, which provide some insight into patient preferences for EOL communication behaviours. Another strength is the set of strategies used to ensure rigour of the qualitative findings. These include debriefing sessions between the two authors who conducted data analysis, the use of the 'thoughtful clinician test', a type of member checking strategy in which emerging interpretations were presented to interview participants for feedback and the fact that only one person conducted interviews in order to ensure consistency.

This study also has some limitations. First, although the qualitative sampling strategy attempted to include non-Caucasians, only Caucasians agreed to take part in the interviews. Patients were recruited from tertiary care academic centres, and thus experiences may be different in smaller community hospitals or in outpatient settings. We have only included participants who endorsed having had an EOL conversation with a physician in the past, and future studies may also include participants who have not had any EOL conversations in order to understand how they would like their physician to initiate such a conversation. However, when participants had only limited personal experience in EOL communication, they were invited to discuss past experiences they have had in engaging in EOL communication with a physician on behalf of a family member as this was felt to be an informative experience. Our qualitative sample is relatively small, but we have made no claims to understand all variations in patient perspectives on physician behaviours during EOL communication. As such, we feel that the sample size is sufficient to provide some insight into the topic of interest while remaining aware that other perspectives may exist. This study focused on communication encounters between seriously ill patients and their physicians; thus, the results cannot be generalised to other members of the multidisciplinary healthcare team. However, by focusing our work on patient-physician communication, the depth and richness that we obtained was likely greater than what may have occurred had we broadened the scope of our study to include encounters with other healthcare providers.

We have obtained data directly from hospitalised patients about the kinds of physician behaviours they would find helpful during EOL conversations. Satisfactory EOL communication between a physician and patient likely requires an ability to appreciate the variability in

patient preferences and to assess individual needs. However, our findings suggest that there are certain behaviours and practices that are perceived to be desirable, such as those outlined in the themes 'knowing me' and 'conditional candour'. The provision of high-quality EOL communication is a challenging task, and while our study provides some potentially helpful recommendations, physicians are likely to benefit from evidence-informed communication skills training. Our study findings may be used in such training activities, and may also be used to inform the design of complex intervention studies aimed at improving physicians' EOL communication skills.

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#### REFERENCES

1. Curtis J, Wenrich MD, Carline JD, *et al.* Understanding physicians' skills at providing end-of-life care: perspectives of patients, families and health care workers. *J Gen Intern Med* 2001;16:41-9.
2. Sudore RL, Fried TR. Redefining the "planning" in advance care planning: preparing for end-of-life decision making. *Ann Intern Med* 2010;153:256-61.

3. Heyland DK, Cook DJ, Rocker GM, *et al.* Defining priorities for end-of-life care in Canada. *CMAJ* 2010;182:E747–52.
4. Heyland DK, Groll D, Rocker G, *et al.* End-of life care in acute care hospitals in Canada: a quality finish? *J Palliat Care* 2005;21:142–50.
5. Heyland DK, Cook DJ, Rocker GM, *et al.* The development and validation of a novel questionnaire to measure patient and family satisfaction with end-of-life care: the Canadian Health Care Evaluation Project (CANHELP) questionnaire. *Palliat Med* 2010;24:682–95.
6. Patton M. *Qualitative evaluation and research methods*. Beverly Hills, CA: Sage Publications, 1990.
7. Alano GJ, Pekmezaris R, Tai JY, *et al.* Factors influencing older adults to complete advance directives. *Palliat Support Care* 2010;8:267–75.
8. Smith AK, McCarthy EP, Paulk E, *et al.* Racial and ethnic differences in advance care planning among patients with cancer: impact of terminal illness acknowledgement, religiousness, and treatment preferences. *J Clin Oncol* 2008;26:4131–7.
9. Lunney JR, Lynn J, Hogan C. Profiles of older medicare decedents. *J Am Geriatr Soc* 2008;50:1108–12.
10. Thorne S, Kirkham SR, MacDonald-Emes J. Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. *Res Nurs Health* 1997;20:169–77.
11. Thorne S. Conceptualizing findings. In: *Interpretive description*. Walnut Creek, CA: Left Coast Press, 2008:163.
12. Thorne S. Strategizing a credible study. In: *Interpretive description*. Walnut Creek, CA: Left Coast Press, 2008:98.
13. Creswell JW. Five qualitative approaches to inquiry. In: *Qualitative inquiry and research design*. 2nd edn. Thousand Oaks, CA: Sage Publications, 2007:53.
14. Thorne S, Kirkham SR, O'Flynn-Magee K. The analytic challenge in interpretive description. *Int J Qual Methods* 2004;3:1–11.
15. Thorne S. Framing a study design. In: *Interpretive description*. Walnut Creek, CA: Left Coast Press, 2008:73.
16. Sudore RL. Can we agree to disagree? *JAMA* 2009;302:1629–30.
17. Hines SC, Glover JJ, Holley JL, *et al.* Dialysis patients' preferences for family-based advance care planning. *Ann Intern Med* 1999;130:825–8.
18. Ozanne EM, Partridge A, Moy B, *et al.* Doctor-patient communication about advance directives in metastatic breast cancer. *J Palliat Med* 2009;12:547–53.
19. Clarke G, Hall RT, Rosencrance G. Physician-patient relations: no more models. *Am J Bioeth* 2004;4:W16–19.
20. Kirby E, Broom A, Good P, *et al.* Families and the transition to specialist palliative care. *Mortality* 2014:1–19.
21. Kryworuchko J, Stacey D, Peterson WE, *et al.* A qualitative study of family involvement in decisions about life support in the intensive care unit. *Am J Hosp Palliat Med* 2012;29:36–46.
22. Davison SN. Facilitating advance care planning for patients with end-stage renal disease: the patient perspective. *Clin J Am Soc Nephrol* 2006;1:1023–8.
23. Thorne S, Armstrong E, Harris SR, *et al.* Patient real-time and 12-month retrospective perceptions of difficult communications in the cancer diagnostic period. *Qual Health Res* 2009;19:1381–94.
24. Davidson PM. Difficult conversations and chronic heart failure: do you talk the talk or walk the walk? *Curr Opin Support Palliat Care* 2007;1:274–8.
25. Davison SN, Seija KK, Currie GR. Patient and health professional preferences for organ allocation and procurement, end-of-life care and organization of care for patients with chronic kidney disease using a discrete choice experiment. *Nephrol Dial Transplant* 2010;25:2334–41.
26. Baile WF, Buckman R, Lenzi R, *et al.* SPIKES—a six step protocol for delivering bad news: application to the patient with cancer. *Oncologist* 2000;5:302–11.
27. Back AL, Trinidad SB, Hopley EK, *et al.* Reframing the goals of care conversation: “we're in a different place”. *J Palliat Med* 2014;17:1019–24.
28. Sullivan MD. Hope and hopelessness at the end of life. *Am J Geriatr Psychiatry* 2003;11:393–405.
29. Schildmann J, Ritter P, Salloch S, *et al.* ‘One also needs a bit of trust in the doctor...’: a qualitative interview study with pancreatic cancer patients about their perceptions and views on information and treatment decision-making. *Ann Oncol* 2013;24:2444–9.
30. Moss AH, Lunney JR, Culp S, *et al.* Prognostic significance of the surprise question in cancer patients. *J Palliat Med* 2010;7:837–40.