

Understanding patients' and doctors' attitudes about shared decision making for advance care planning

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Abstract

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Background Although shared decision making (SDM) is the preferred model of making complex treatment decisions with patients, patients' and doctors' attitudes towards SDM for advance care planning are unknown.

Objective We sought to: (i) gain general insights into the current practice of SDM and attitudes about patient involvement, and (ii) gain specific insights into experience with, and attitudes about, SDM for advance care planning.

Design Qualitative analysis of face-to-face semi-structured interviews.

Setting and participants Patients with chronic lung disease and their doctors at a New York City public hospital.

Results Although patients described participation in decision making, many deferred the final decision to their doctors. Doctors indicated a preference for SDM but expressed barriers including perceived lack of patient understanding and lack of patient empowerment. With regard to end-of-life discussions, patients were generally open to having these discussions with their doctors, although their openness sometimes depended on the circumstance (i.e. end-of-life discussions may be more acceptable to patients for whom the chance of dying is high). Doctors reported engaging in end-of-life treatment decisions with their patients, although expressed the need for conversations to take place earlier, in advance of acute illness, and identified a lack of prognostic estimates as one barrier to engaging in this discussion.

Conclusions Doctors should explore their patients' attitudes regarding end-of-life discussions and preferences for decision-making styles. There is a need for tools such as decision aids which can empower patients to participate in decision making and can support doctors with prognostic estimates pertinent to individual patients.

Introduction

Advance care planning is the process by which patients prepare for what treatments they would accept in the event of critical and potentially terminal illness (end-of-life decisions). This planning includes discussing options for treatment and prognosis as well as appointing surrogate decision makers. Some choose to complete written directives in the form of Advance Directives. In theory, planning in advance allows patients and their surrogates to be more prepared to make end-of-life decisions. Although most patients are open to discussing end-of-life issues, few have had such conversations with a doctor.¹

In patients with chronic diseases, doctors with whom they have long-standing relationships could uniquely assist with informing patients about their disease prognosis, treatment options in the event of critical illness and likely outcomes. Further, doctors could also engage with patients to elicit their preferences and to help them arrive at decisions congruent with these informed preferences. This process of informing and preference elicitation to assist with decision making is known as shared decision making and has become the standard model for collaboration between patients and their doctors to make health decisions.^{2–6} Shared decision making is supported in part because it has been shown to decrease patients' uncertainty and conflict about their decisions.⁴ However, patients' preferences for involvement in decision making is variable⁷ and may depend on the type of decision. For advance directive decisions, studies suggest that many patients are open to doctors discussing their prognosis in advance of critical illness, especially if they have < 1-year life expectancy.⁸ However, cultural differences may affect preferences regarding medical decision-making styles/models.^{9–11} This is especially pertinent for emotionally charged conversations such as mortality prognosis for patients with severe stage chronic disease.

Few studies have examined patient and doctor preferences for shared decision making

regarding end-of-life decisions (shared advance care planning).^{12,13} Research has shown discrepancies between patients and doctors on their desired role in decision making¹⁴ as well as on initiation, timing and content of end-of-life discussions. One review of end-of-life discussions for chronic obstructive pulmonary disease patients found that many doctors felt uncomfortable initiating such conversations and preferred that patients did so.¹ However, another study suggested that most patients wanted their doctors to initiate end-of-life discussions.¹⁵ This lack of consensus about who should initiate end-of-life discussions and when these discussions should take place has been identified as a barrier to advance care planning.¹⁶ One study found that patients want discussions earlier and with greater honesty than doctors may perceive.¹⁷ In addition, patients may desire to be very involved in the decision making but may prefer that the doctor makes the actual decision, albeit considering the preferences and concerns they expressed in the process. This has been termed as collaborative decision making rather than shared decision making which implies the decision was made together.¹⁸ Doctors may be hesitant to make a decision for a patient given the emphasis on shared decision making as the ideal framework for arriving at value-sensitive decisions. As patient preferences vary, recommendations suggest that end-of-life conversations be patient-centred, with the content, timing and place determined by the patient, but more research is needed on patient preferences for these discussions.¹ Several studies have concluded that end-of-life discussions should be on-going since, as the clinical condition changes, or the patient becomes more informed of his or her condition or prognosis, preferences for care and desired involvement may change.^{1,13,19}

In prior work, we designed a decision aid prototype to support shared advance care planning at the point of outpatient clinical care, for patients with severe chronic obstructive pulmonary disease. In order to begin to assess whether such a decision aid would be acceptable to patients and their doctors, and conscious of

the sparse data regarding attitudes about shared advance care planning, we designed a study to explore these attitudes. In particular, we were interested in attitudes of socio-economically underserved patients and their doctors at Bellevue Hospital, a public inner-city hospital that serves mostly socio-economically disadvantaged patients in New York City. We sought to gain insights into whether patients and doctors were engaging in shared decision making in general and attitudes about patient involvement in shared decision making. We also sought to gain specific insights into experience with and attitudes about shared decision making for advance care planning including doctor initiation of the discussion, timing of the discussion and the use of prognostic estimates.

Methods

Study design and sample characteristics

Data for the present analysis were obtained from face-to-face, in-depth semi-structured interviews conducted in an outpatient pulmonary clinic at Bellevue Hospital in New York City, from 28 May to 10 June 2013. Five doctors and 11 patients were interviewed about current practices and attitudes regarding shared decision making and end-of-life decision making. The New York University School of Medicine Institutional Review Board approved all the study protocols. Participants received a gift card with the value of \$75 (patient participants) or \$100 (doctor participants) for completing the study.

Data collection

Trained research staff conducted the semi-structured interviews. Interviews lasted approximately 30–60 min, with interviewers asking questions about patients' and doctors' attitudes and perceptions towards shared decision making and end-of-life decision making. Examples of questions included can be found in Table 1. Interviewers were trained to ask additional probing questions based on participant res-

ponses. All the interviews were transcribed, coded and analysed using NVivo 10 software.²⁰ When patients and/or doctors reported not having heard of a particular topic (e.g. advance directives, health-care proxy and mathematical models) interviewers prompted the participants with a standard definition. The Appendix provides the definitions prompted in the interviews.

Embedded into the semi-structured interviews were closed-ended questions. The purpose of the closed-ended questions was to quantify specific preferences among the participants in order to have a better understanding of their opinions. Patient participants responded to six closed-ended questions related to: (i) preferences for decision making (1–5 ranking), (ii) preferences if unable to make decisions (1–5 ranking), (iii) trust (0–10 scale, 0 = not at all, 10 = very much), (iv) knowledge (yes or no), (v) experience with end-of-life decision making (yes or no) and (vi) attitudes towards shared end-of-life decision making (yes or no). Furthermore, clinician participants responded to two closed-ended questions related to: i) decision making (1–10 scale, 1 = let the patient make decision on his/her own, 10 = doctor makes decision for the patient). Table 3 depicts the closed-ended questions utilized in the study.

Data analysis

Qualitative data analysis

Interview transcripts were coded, sorted and compared using a constant comparative analysis. A constant comparative analysis is an inductive process originally developed for use in grounded theory that is now applied more widely as a methodology of analysis in qualitative research.²¹ The analytic process included the following: (i) generating codes to be attached to similar quotes or topics across transcripts, (ii) comparing and contrasting ideas related to the codes to create themes that fit the nature of the data and (iii) assessing the reliability of codes and themes. The analysis centred on key issues related to end-of-life decision making such as the timing, characteristics of the context in which these discussions

Table 1 Sample questions included in participant interviews

| Aim | Interview question |
|--|--|
| 1 – Current practice of shared decision making (SDM) | What are your experiences when you had to make a decision about a treatment or a test with your doctor? |
| 1 – Current practice of SDM | How involved are you in making health decisions with your doctor? |
| 1 – Attitudes about patient involvement in decision making | In the future, you are likely to have to make some very important decisions about your health. . . How involved do you think you would want to be in making health decisions with your doctor? |
| 2 – SDM in advance care planning | When patients reach the end of their life they need to make some important decisions about their health care, do you have examples of what kind of decisions they may need to make? |
| 2 – SDM in advance care planning | Have you ever talked about end-of-life decisions with your doctor, for example, whether you would want to be treated with a breathing machine? |
| 2 – SDM in advance care planning | Have you ever talked with your doctor about your chance of dying from your disease? |
| 2 – SDM in advance care planning | Under what circumstances should discussions about end-of-life decisions take place? |
| 2 – SDM in advance care planning | What should the goals of such a discussion be? |

should take place, the use of prognostic estimates and doctors' and patients' attitudes towards end-of-life decision making. The analytic approach was informed by sensitizing concepts. Sensitizing concepts refer to previously studied ideas that provide reference and guidance in approaching an empirical inquiry.²³ In the context of this study, sensitizing concepts were previously studied domains important for end-of-life decision making. Several strategies to ensure the scientific rigour of the analytic approach were employed including peer debriefing within the analysis and data collection, independent and collaborative coding of transcripts and the use of memo-writing to aid in the development of ideas as well as providing a decisional audit trail.²²

Quantitative data analysis

We undertook a descriptive approach to characterize participants' responses to the closed-ended questions. Median and range were calculated for the items using rank order and scales. Number of responses and percentages were calculated for the dichotomous (yes/no) questions.

Results

Eleven of 52 patients who were approached and met inclusion criteria for the study agreed to

participate. The most common reason given for declining to participate was time constraints. The socio-demographic characteristics of the participants are summarized in Table 2. The median age for patient participants' was 60 years (Range = 23–73 years). All the patient

Table 2 Participant characteristics

| | Patients N = 11 No. (%) | Doctors N = 5 No. (%) |
|--|-------------------------------|-----------------------------|
| Age, Median (Range) | 60 (23–73) | 32 (30–46) |
| Gender | | |
| Female | 5 (45) | 2 (40) |
| Male | 6 (55) | 3 (60) |
| Race/Ethnicity | | |
| Hispanic/Latino | 7 (64) | 0 (0) |
| Black/African American | 3 (27) | 0 (0) |
| White | 0 (0) | 3 (60) |
| Asian/Asian American | 1 (9) | 2 (40) |
| Education ¹ | | |
| <8th grade | 2 (18) | |
| 9th–12th grade | 5 (45) | |
| Some college | 2 (18) | |
| College degree | 2 (18) | |
| Years of training after medical school | | |
| 0–5 | | 2 (40) |
| 6–10 | | 2 (40) |
| 11+ | | 1 (20) |

¹All doctors were medical doctors (pulmonologists). Percentages may not sum to 100% due to rounding.

participants identified themselves as belonging to a racial/ethnic minority group (64% Hispanic/Latino, 27% Black/African American and 9% Asian/Asian American). Most patient participants were men (55%) and had an educational level of less than or equal to a high school diploma (63%). With regard to the doctor participants, most were white men (60%), the median age was 32 years (Range = 30–46 years) and most had completed more than or equal to 6 years of post-medical school training (60%).

The themes related to shared decision making and advance care planning that emerged from the patients' and doctors' narratives are described below. Table 3 summarizes the responses of both patients and doctors to the closed-ended questions including questions relevant to shared decision-making practices and preferences.

Current practice of shared decision making and attitudes about patient involvement

Patient participants

Patients were asked how they make decisions with their doctors. Most patients identified several elements of shared decision making in the way they interact with their doctors, including exchange of information regarding the consequences of a decision and establishing discussions with the purpose of reaching consensus. In fact, the majority of the patients expressed that they prefer to share responsibility with their doctors for making decisions about their treatment (Table 3). However, in most cases, patients expressed that doctors have the final word in clinical decisions. As one patient explained,

'She [the doctor] tells me what medication to take, how to do it, and I know it's going to be good for me because if not she would tell me. She knows me and I know her for so many years'. (Patient, Female, 65)

Doctor participants

Most doctor participants articulated that they usually 'have the final word' on clinical decisions. For example,

'I usually just say what I think is the best recommendation, sometimes I try to involve them [the patients] into the decision-making process. I would say: ultimately this is your choice, but this is probably what I would do if it was my family member. I would recommend what is best for the patient'. (Doctor, Male, 33)

However, when asked to rate their preferences for making decisions with their patients, most doctors preferred a shared style of decision making (Table 3). Despite this preference, doctors identified several conditions that limit their ability for shared decision making. One barrier identified was a perceived lack of patients' ability to comprehend medical data. For example,

'It depends on what the patient understands about the diagnosis. That is the first kind of process that has to happen, you know, engaging the patient in terms of their level of understanding of what diagnostic possibilities are, and asking their understanding. Once you kind of gather the level of understanding that the patient has, and maybe wants to have about their diagnosis, and what their biases are going in, and everything like that'. (Doctor, Male, 32)

Another barrier to shared decision-making doctors identified was a perceived lack of patient empowerment to participate in decision making. As one doctor said,

'Today there's a strong emphasis on patient autonomy. I believe we [doctors] can provide patients the information and help them, make some recommendations in terms of their further care, but ultimately they give us the yes or no, or raise concerns when they have them. But, I don't think that patients do know that [they can be involved in the decision making]'. (Doctor, Male, 30)

Other factors that doctors articulated as potential barriers to shared decision making, included patients' cultural background and language. For example,

'The cultural background definitely plays a role in how patients make decisions. Ultimately the patients decide for themselves and have the autonomy to either decline certain testing, or to ask for other testing, or various treatment options. Sometimes we can be flexible and make some alterations in those things. For example,

Table 3 Patients' and doctors' responses to closed-ended questions

| Measures | Results |
|--|-----------|
| <i>Patient responses</i> | |
| Preferences for decision making (1–5 rank order, 1 = most preferred, 5 = least preferred), <i>Median (Range)</i> | |
| Prefer to make decision about which treatment will receive | 4 (1–5) |
| Prefer to make decision about treatment after considering doctor's opinion | 2 (1–4) |
| Prefer to share responsibility with doctor for deciding about treatment | 1 (1–3) |
| Prefer doctor make decision about treatment after considering his/her opinion | 3 (2–4) |
| Prefer to leave all decisions regarding treatment to doctor | 5 (2–5) |
| Preferences if were unable to make decisions, (1–5 rank order), <i>Median (Range)</i> | |
| Prefer family/loved ones make decision about treatment | 4 (1–5) |
| Prefer family/loved ones make decision about treatment after considering doctor's opinion | 3 (1–5) |
| Prefer doctor and family/loved ones share responsibility for deciding about treatment | 3 (1–4) |
| Prefer doctor makes the final decision about treatment, but considers the opinion of family/loved ones | 3 (1–4) |
| Prefer to leave decisions about treatment to doctor | 5 (2–5) |
| Trust (0–10 scale, 0 = not at all, 10 = very much), <i>Median (Range)</i> | |
| 'How much do you trust your doctor?' | 10 (6–10) |
| 'How much would you trust a decision your doctor made for you?' | 10 (6–10) |
| Knowledge, (Yes/No), <i>No. (%)</i> ¹ | |
| Knows patients have the right to say no to a breathing machine | 8 (73%) |
| Knows patients have a right to say no to being taken to the hospital | 9 (82%) |
| Has ever heard of an advance directive | 3 (27%) |
| Has ever heard of a health-care proxy | 11 (100%) |
| Experience with end-of-life decision making, (Yes/No), <i>No. (%)</i> ¹ | |
| Has ever talked with his/her doctor about his/her chance of dying from his/her disease | 1 (9%) |
| Has ever talked about end-of-life decisions, for example whether he/she would want to be treated with a breathing machine, with his/her doctor | 4(27%) |
| Attitudes towards shared end-of-life decision making,(Yes/No), <i>No. (%)</i> ¹ | |
| Thinks doctors should talk with their patients about their patient's chance of dying from their disease | 8 (73%) |
| Thinks doctors should talk about what choices patients have about treatments at the end of life | 10 (91%) |
| Thinks doctors should help patients to make advance directives | 7 (64%) |
| <i>Doctor responses</i> | |
| Decision Making (1–10 scale, 1 = let the patient make decision on his/her own, 10 = doctor makes decision for the patient without considering their opinions), <i>Median (Range)</i> | |
| Self-rated style when making medical decisions relevant to patients | 6 (4–7) |
| End-of-life Decision Making, (Yes/No), <i>No. (%)</i> ¹ | |
| Has end-of-life discussions with patients | 5 (100%) |
| Discusses decision making or preparation for end of life with patients who have severe chronic diseases | 5 (100%) |
| Discussions about end-of-life care should take place at clinic visit | 3 (60%) |
| Doctors should be involved in decision making about end of life | 4 (80%) |
| Doctors should be required to initiate end-of-life discussions with their patients | 3 (60%) |
| Aware of mathematical models which can calculate outcomes/prognostic estimates for patients with certain chronic diseases, such as HIV or chronic obstructive pulmonary disease (COPD) | 3 (60%) |

¹Percentages reflect the amount of participants that expressed this particular response; some participants did not express any response (positive or negative).

one case comes to mind. Recently I had a patient from Bangladesh, a female who preferred to have her husband make decisions on her behalf, so we used an interpreter just to document those preferences and then we took that into consideration and abided by that request'. (Doctor, Male, 30)

Experience with, and knowledge about, end-of-life decision making

Patient participants

Some patients (27%) reported having talked with their doctors about end-of-life decisions

(Table 3). For example, when asked about his experience discussing end of life, a participant said,

'I had that conversation with my doctor. Basically the conversation centred on if I am not able to do something, and whether or not I would want to be, you know, hospitalized. It was more generic questions about end-of-life, like what you would do, but then again, we had not come to any kind of plan or conclusions. They were just questions put out there, you know, for me to consider'. (Patient, Male, 64)

Those who reported not having discussed end-of-life decisions with their doctors did indicate that they were willing to have these conversations.

Most patient participants related to the importance of end-of-life decision making through the experience with a family member. For example,

'I can tell you about the case of another person. My brother was within minutes of death but he was still conscious of what the doctor had told him and he made all the decisions and signed the papers. In that case I would like the same to happen with me'. (Patient, Male, 60)

When asked their preferences regarding physician involvement in end-of-life decision making, some patients referenced prior experience with end-of-life decision making. For instance, when asked whether she thought doctors should talk about what choices patients have about treatments at the end of life, one participant responded:

'Yeah, I think so. For example, my grandfather died of lung cancer and I discuss with the doctor, the attending physician, where- what is the treatments out there, what the percentage of survival?' (Patient, Female, 35)

The majority of the patient participants knew that they have the right to say no to a breathing machine (73%) and say no to being taken to the hospital (82%; Table 3). All of them had previously heard of a health-care proxy (100%). However, only 27% of the participants had ever heard of an advance

directive (which was described as a legal document that allows you to put into words your choices about end-of-life care ahead of time; see Appendix). After being prompted on what an advance directive was, most patients expressed the desire to complete an advance directive. One participant articulated this view by saying,

'Yes, it would be very important to me...because my mother died and she didn't leave one, and I was the oldest and the whole responsibility was on my shoulders. And then I had a fight with the rest of the family, because some wanted one thing and the other, and I had a big problem with that'. (Patient, Female, 70)

Doctor participants

All the doctor participants had previous experience discussing end-of-life decisions with their patients. In most cases doctors referred to these experiences in the context of intensive care. For example,

'Usually I approach patients and their family members. If someone is not comatose and they are scared and distressed it's not the best time to bring up to them that they might not do well. Umm, before they are scared and distressed and they're very ill, it's a good time to talk to them about their preferences. But in a lot of critical care situations, it's the patient's surrogate that we meet and I am very upfront with surrogates about talking about how sick their loved ones are and I bring it up. I initiate the conversation'. (Doctor, Male, 32)

Attitudes towards shared end-of-life decision making including doctor initiation and discussion timing

Patient participants

Most patients agreed that their doctors should be involved in the end-of-life decision-making process. As one patient said,

'Yeah, I think that doctors should be involved because they understand the medical [implications], you know, that's their expertise'. (Patient, Male, 64)

We asked several questions to elicit attitudes about shared decision making for end-of-life

decisions and advance care planning. In response to the question ‘Do you think doctors should talk with their patients about their patient’s chance of dying from their disease?’. One patient participant stated,

‘Yes, because, if one is able to understand, they could, between the doctor and I, discuss how to prolong life a little more’. (Patient, Male, 60)

And in response to the question “Do you think doctors should help patients to make advance directives?” the same participant stated,

‘[The doctor should help make an advance directive] well, because they’re more experienced than I am’.

When asked whether doctors should initiate this discussion, the participant stated:

‘[The doctor should] begin the conversation... because they are more aware of the diseases one has and they could teach us about it’.

Other patient participants stated,

‘[Doctors should talk to their patients about treatment options at end-of-life] ‘cause this way you take more conscience of, you know, what’s happening to you, what you should do in advance, if it’s needed’. (Patient, Female, 65)

And,

‘[Doctors should talk with their patients about their chance of dying] ‘cause it’s something that they should do. I think that they are doctors... and that’s their job to talk with their patients about their disease and about, you know, what they could do for themselves.....They will enlighten the person. It gives them, umm, something to think about. Something to focus and think about which way they want, you know, what they wanna do with their lives...like with their medication’. (Patient, Male, 49)

Patient participants also expressed concerns about doctors engaging in these discussions. One participant considered that talking with a lawyer would be more appropriate,

‘It’s not their [doctors] responsibility [to help patients make advance directives] because I want them to be focused on treatments, more on survival. Wouldn’t it be a legal professional, a

lawyer, which would handle that situation, like the law of the courts and the policies. Because doctors are not lawyers.... Based on the disease, the advanced state of the disease, maybe it’s best to discuss this with them [doctors], but if they’re not in that area why should you focus on that...’. (Patient, Female, 35)

However, the same participant expressed fear of even considering the end of life,

‘That issue [end-of-life decision making] hadn’t come up yet so hopefully I don’t have to decide that criteria, so no, not now. Don’t even want to think about it’. (Patient, Female, 35)

Another participant expressed hesitation,

‘I believe that patients have an idea that will happen [end-of-life], but I don’t know if it’s a good idea to talk about that. I mean, when you talk about death you start thinking and thinking and I guess, I don’t know’. (Patient, Female, 70)

Interestingly, when we asked this participant more questions about discussing end of life with her doctor, her opinion changed. She felt that doctors should talk about end of life with patients in certain circumstances (i.e. patients for whom the chance of dying is high). The participant later stated,

‘I said no at the beginning [to doctors talking about end-of-life]. But, you know, if they see that the patient is getting worse and there is no way that they could do anything with the patient then they should talk to the patient about dying. So they [patients] have time to fix whatever needs to be fixed and they should have preparation’. (Patient, Female, 70)

Doctor participants

The majority of doctors believed that end-of-life discussions should take place during outpatient clinic visits (60%), that doctors should be involved in the decision-making process (80%), and believed that doctors should be required to initiate these discussions (60%; Table 3). Doctors seemed to feel that certain environments and contexts are more conducive to shared decision making than others. As one doctor stated,

‘I think it [end-of-life discussions] should take place with their [patients] primary care doctors when they’re not in a situation that requires an

immediate decision. It should be something that, you know, when they have the right state of mind to know what their wishes are and do not have to rush into a decision. As opposed to when they're actually in a life-threatening emergency and you have to make an immediate decision. I think that is less favourable for them. Any middle aged to elderly patient, or any other patients who have a lot of medical problems, should have these discussions'. (Doctor, Male, 33)

Doctor participants expressed that end-of life discussions should address the following topics: patients' possible outcomes and their impact on their quality of life, patients' preferences in term of treatment (e.g. ventilator, chest compressions, and defibrillation), patients' preferences in the case of no reasonable chance of recovery, whether patients would like to identify a health-care proxy or surrogate, whether they have previous living wills or advance directives, and the option of not receiving treatment. For example, one doctor stated,

'Patients need to know how much they can live functionally. They need to know the treatment options, that the treatment doesn't guarantee life or better quality of life or even like prolonged lifespan, so they need to know they have the option of not to be treated'. (Doctor, Female, 32)

Doctors did, however, identify time constraints within the clinic visit as a barrier to shared end-of-life decision making. For example,

'I think that it takes a lot of time to discuss those things and sometimes it's difficult to do a focused assessment of their disease at that point and do an end-of-life discussion at the same time. I think it's probably useful to actually have a separate visit or separate time to do that. I think it would be more effective with more time and more options for the patient and the family to ask questions'. (Doctor, Male, 30)

Doctors' attitudes about the use of prognostic estimates for shared advance care planning

Despite the fact that all the interviewed doctors endorsed having end-of-life discussions, most

expressed discomfort and/or resistance discussing prognostic estimates such as life expectancy with their patients. For example, one doctor expressed this view by saying,

'Um, I have done that [discussing life expectancy] on a few occasions, but it is difficult and, um, and on a couple of occasions the patients have not been receptive to that'. (Doctor, Male, 30)

With regards to prognosis, many doctors (60%) were aware of mathematical models which can calculate outcomes/prognostic estimates but had limited experience using these models. For example, one doctor said,

'In papers, I have read about mathematical models that predict exacerbation, or scoring systems that predict quality of life outcomes, or I don't know, I think other ones that predict mortality too, but I don't use them in practice'. (Doctor, Male, 32)

Another doctor said,

'I don't feel like I have enough knowledge or familiarity with mathematical models to sort of speak to it or use them in my practice'. (Doctor, Female, 46)

Discussion

Our study aimed to provide insights into patient and doctor experiences and attitudes regarding shared decision making, both in general, and specifically for end-of-life decision making. We found that although patients described participation in decision making, many deferred the final decision to their doctors. Politi *et al.*¹⁸ describe a process of 'collaborative' decision making in which patients *co-operate* with their doctors (and family members) in the decision making and may be highly involved, yet 'chose to defer the decision to the doctor'. The findings of our study suggest a more collaborative form of decision making is desired by patients although our questions were not designed to understand to what degree this may potentially have been due to a lack of patient empowerment.

Opportunities for increasing patient participation in decision making during the clinical

encounter for patients who would like to participate more include having tools that can explain medical terms and prognosis in patient-centred language and explicitly empowering patients to be more active in decision making. Opportunities also exist for providing doctors with access to prognostic estimates and to increase their trust in these estimates. Patient-specific/personalized estimates may increase doctors' trust in estimates and make them more likely to share these with their patients. Education and transparency regarding the evidence supporting these estimates and methods used to minimize error could also improve uptake and communication about prognostic estimates.

With regard to advance care planning, opportunities exist for patients to be more informed about resources to assist with planning and allowing patients to incorporate their experiences with families and friends at the end of life. Our results suggest that one of the barriers to shared decision-making in end-of-life communication is patient avoidance of advance care planning discussions. However, if the prognosis was poor, patient participants did support doctor-initiated discussions about prognosis and end-of-life treatment choices. These findings suggest that patients may find doctor-initiated discussion about advance care planning to be more acceptable if patients have poor prognosis. Doctors should explore their patients' attitudes regarding these discussions, with the knowledge that some patients may be more accepting of engaging in this discussion when they are presented with prognostic estimates indicating a limited life expectancy.

Opportunities for refinement of a decision aid to support doctor–patient shared decision making about end-of-life treatments that were identified by our study include: a decision aid that is tailored for patients with poor prognosis, a decision aid that empowers patients to play an active role in these decisions if they choose to take on this role, framing discussions about end-of-life treatment options through the lens of patients' experiences with family and friends who have died, discussing preferences

for treatments if there was no reasonable chance of recovery, and explicitly describing predictions for quality of life. Communication of prognostic estimates needs to carefully describe how the data is generated, and doctors need evidence that patients would be 'receptive' to their discussions about life expectancy and prognosis. These findings will inform the redesign of our decision aid prototype to support shared advance care planning at the point of outpatient clinical care, for patients with severe chronic obstructive pulmonary disease.

Strengths and limitations

In this study, the use of qualitative methods allowed for insight into doctors' and patients' views towards shared decision making for advance care planning. Nevertheless, the findings should be interpreted within the study's limitations. Although the results are not intended to be generalizable, the use of an urban clinical population may limit the breadth of the data. First, the experience of patient and doctor participants may be limited by the context. Further, variability may exist by age, gender, race/ethnicity and characteristics of the clinical diagnosis. Although we are reporting participants' age and gender, the sample does not allow considering variations by axis of diversity. In addition, the sample was restricted to patients proficient in English or Spanish. Participants that speak other languages and have a different cultural background might express different opinions. Despite these limitations, several strategies to increase the rigour of the study were pursued including peer debriefing, independent and collaborative coding, memo-writing and the use of a decisional audit trail.

Conclusions

Patients studied generally wished to be involved in decision making with their doctor. Doctors indicated a preference for shared decision making but expressed some barriers including perceived lack of patient understanding and lack of patient empowerment. With

regard to end-of-life discussions, patients were generally open to having these discussions with their doctors, and doctors reported engaging in advance care planning with their patients, although expressed the need for conversations to take place earlier, in advance of acute illness. Our study results can inform the development of tools such as decision aids which may empower patients to participate in decision making regarding their health care and can support doctors with prognostic estimates pertinent to individual patients.

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Conflicts of interest

None.

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Appendix

Definitions given to patients during interview

An advance directive is a *legal document* that allows you to put into words your choices about end-of-life care ahead of time. With an advance directive, you can make your wishes known to family, friends and healthcare providers ahead of time. It tells your doctor what kind of care you would like in case you are unable (too sick) to make medical decisions.

A health-care proxy is someone you choose to make health-care decisions for you if you lose the ability (are too sick) to make decisions yourself.

Definitions given to physicians during interview

A mathematical model is also known as a Markov model, decision analytic model or simulation model. In brief, these models combine quantitative evidence-based data information from such as from published clinical studies, to determine the mathematical probabilities/likelihoods of outcomes if people choose from between at least two different options (treatments, medications etc). A major purpose of decision analysis is to assist in comprehension of the problem, such as what factors should be considered in choosing between Drug A or B and to give us insight into what variables or features of the problem should have a major impact on our decision.²³ For example, if we find that patients would likely live longer if they had less complications at a certain point in the course after they take Drug A, we can integrate this into the decision about whether or not to take Drug A vs. Drug B. We can also use a decision model to allow people to recognize the potential tradeoffs, for example between survival and quality of life as a result of medication complications, which may need to be considered when making the choice.