

Engaging death: Narrative and constructed dialogue in Advance Care Planning discussions

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Abstract

Advance Care Planning (ACP) remains extremely low in the US, due to numerous institutional and cultural barriers and discomfort in discussing death. There is a need for guidance about how patient and healthcare providers can effectively engage in ACP discussion. Here we analyze the linguistic strategies that focus-group participants use when discussing ACP in detailed ways. Prevalent linguistic structures in effective ACP discussions were loved ones' end-of-life narratives, hypothetical narratives, and constructed dialogue. In elucidating spontaneous, unprompted approaches to effective discussion of end-of-life issues, such research can help to dislodge communicative barriers to ACP so that more people are prepared to engage the process.

Keywords: advance care planning; constructed dialogue; end-of-life; hypothetical narrative; narrative; reported speech; quotatives

1. Introduction

Advance Care Planning (ACP) is a process developed to clarify personal preferences and create a written advanced directive (AD) for future medical decisions in the event of decision-making incapacity (Curd 1999; Levi and Green 2010). ACP helps patients reflect on their goals, values, and beliefs, consider future medical treatment, appoint a surrogate decision-maker, and

document their wishes regarding future treatment (Detering *et al.* 2010). ACP is associated with a variety of favorable outcomes: improved satisfaction with care, improved quality-of-life in terminal illness, better psychological outcomes for grieving family members after patient death (Heyland *et al.* 2009; Zhang *et al.* 2009; Detering *et al.* 2010), increased hospice use, reduced intensive-care hospitalization, and decreased health care costs at the end-of-life without compromising quality outcomes (Zhang *et al.* 2009).

ACP discussions usually take place in the context of anticipated deterioration in an individual's condition, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others (NHS Improving Quality 2014). ACP is a notoriously uncomfortable subject for both laypeople and healthcare providers. Consequently, it is surprisingly rare; as Bradley *et al.* (2006) and Temel *et al.* (2010) note, in the US it is between 18% and 31%. The ACP scholarship attributes this not only to general discomfort with death and dying, but also to the lack of an institutionalized infrastructure for ACP; thus healthcare providers have neither the training, time, prognostic prediction ability, nor communication skills to help patients effectively plan for end-of-life in any systematic way (Weiner and Cole 2004; Ramsaroop *et al.* 2007; Coolen 2012). Furthermore, current ACP practices are generally legalistic and impersonal, structured around the framework of the Advance Directive and its dense legal jargon (Gordy and Klein 2011).

Recent years have seen increased research into improving ACP procedures. However, while ACP remains a field centered in communication, study of actual patient talk about ACP remains sparse. Many useful programs provide protocol-based templates for ACP discussions, rather than using patients' experience as the entry point. As Parry *et al.* (2014) note, protocols tend not to address the aforementioned barriers to ACP. Uncertainty about how to conduct ACP discussions often causes providers to shy away from engaging in these important conversations with patients, resulting in late-stage crisis decision-making, when patients cannot communicate (Simpson 2012).

Because we know more about protocols than about how effective ACP discussions unfold, we cannot provide robust education and guidance to providers on how to talk with their patients about end-of-life issues. This contributes to the situation where a majority of patients with terminal illness have not participated in ACP discussions (Kass-Bartelmes and Hughes 2004). In addition, communication between patients, families, and medical providers about end-of-life preferences remains ineffective and inconsistent (Kass-Bartelmes and Hughes 2004). These gaps in knowledge and care demonstrate the need for more fine-grained approaches for understanding ACP communication.

Given that talk is both a critical and critically fraught aspect of ACP, it is profitable to analyze how people, of their own accord, substantively engage and grapple with the details of care around dying. Despite the difficulties of ACP discussions, some people are able to broach the topic of end-of-life effectively and put a comprehensive plan into place. Research into what such talk looks like linguistically can provide material for ACP protocols and procedures that build organically on language choices that people feel comfortable with (as evidenced by their spontaneous use of them at moments of deep engagement), thereby potentially contributing to more effective ACP procedures.

In order to contextualize the study within current conversations in both medical research and discourse analysis, we first describe the current state of Advance Care Planning from the

clinical (medical research) perspective, then lay out our methodology and explain the relevant discourse analysis findings on narrative, the main form of discourse that we analyze. Next, we turn to our data, examining how speakers use hypothetical narratives and narratives of loved ones as a means of articulating perspectives about their own ACP choices. We conclude with a section emphasizing how the characteristics of these particular narrative forms aid in the process of engaging with one's own future incapacitation and death.

2. Research on advance care planning: The clinical perspective

Since 1960, medical advances have resulted in people living longer, often with chronic disease. Concurrently, the rates of iatrogenic disease (disease induced by medical treatment) have increased (Bunker 2001). Patients operate in this increasingly complex and hazardous medical system with limited tools for informed decision-making (Braddock *et al.* 1999, Long 1979). Ethical dilemmas concerning treatment of competent vs. incompetent patients, withdrawal of life-sustaining treatments, and end-of-life guardianship are often debated in the American public sphere. Cases such as Karen Ann Quinlan (McIntyre 1993), Nancy Cruzan (Lo and Steinbrook 1991), and Terri Schaivo (Perry *et al.* 2005) highlight the need for patients to voice and reliably document their preferences for care and preferred healthcare proxies while they are competent, before they are too medically impaired to speak and advocate for themselves (Fairman 1992; Steihauser *et al.* 2000).

The 1990 Patient Self-Determination Act (PSDA) requires hospitals to ask patients about presence of advance directives (AD), record ADs in the medical record, develop institutional policies surrounding AD implementation (Greco *et al.* 1991), and place greater ethical emphasis on patient autonomy (Stiggelbout *et al.* 2004). This has placed value on giving patients a final say in their medical decisions. However, the PSDA has shown limited effectiveness in ensuring that a patient desires all medical care delivered (Teno

et al. 2007). While several factors (e.g. PSDA, the Uniform Health Care Decisions Act of 1993, and state-specific AD laws) have solidified ADs as the primary method of communication about patient end-of-life preferences (Sabatino 2010), numerous studies have established that systematic completion of ADs does not help medical providers better understand patients' medical wishes or needs at the end of life (Teno *et al.* 1997; Sabatino 2010). The inadequacies of AD-based communication may be due to providers not taking time to clarify documented preferences (Byers and Melhado 2011), or due to the vague, transactional language of AD documents (Castillo *et al.* 2011). In 1997, the Institute of Medicine concluded that conventional ADs may 'stand in the way of, rather than ease, the process, especially if these documents are naively viewed as ultimate solutions to the difficulties of decision-making' (Field and Cassel 1997: 203). State-specific ADs used for documenting patient medical preferences for care are rarely used (Kwak and Haley 2005), are poorly understood by patients (Hoffmann *et al.* 1996), have limited clinical application (Teno *et al.* 1997; Teno 1999; Teno *et al.* 2007), are not routinely communicated to healthcare providers (Morrison *et al.* 1995), and do not promote healthcare proxies' understanding of the preferences of the patients whose interests they represent (Shalowitz *et al.* 2006).

These AD limitations have resulted in the development of Advance Care Planning (ACP), a more comprehensive communication-centered approach to end-of-life decision-making (Sabatino 2010). The last 20 years have seen marked progress in the science of ACP, with the development of alternative templates: e.g. Respecting Choices, a program using trained facilitators to conduct ACP discussions (Hammes *et al.* 2010); the Health Values Questionnaire, a questionnaire administered to patients by providers (Karel *et al.* 2004); *Five Wishes*, a patient-completed care document focusing on comfort and spiritual issues (Witkowski *et al.* 2007); and Making Your Wishes Known, an interactive computer-based decision support tool allowing patients to independently record medical care preferences (Green and Levi 2009). These tools aim to supplement state-specific AD forms (living wills and healthcare

powers of attorney) by encouraging patients to voice personal and health-intervention preferences for end-of-life care, discuss preferences with medical providers and appointed healthcare proxies, and promote documentation of these preferences so that medical care may reflect patient wishes during times of crisis when s/he is unable to communicate (Emanuel *et al.* 1995; Aitken 1999; Elwyn *et al.* 1999, Lipkin 2006).

Additionally, the Physician Orders for Life-Sustaining Treatment (POLST) paradigm (Lee *et al.* 2000), developed in Oregon in 1991, converts patient preferences into actionable physician orders and is currently available in 16 states.¹ Although POLST overcomes AD limitations by expressing patient preferences in clear physician medical orders (Lee *et al.* 2000), a lack of nationwide POLST availability limits its widespread use (In der Schmitzen *et al.* 2011), and documentation about patient and provider order decision rationale must be done separately.

ACP has received renewed emphasis in the context of end-of-life care since 2011. National policy organizations have emphasized the importance of consistently integrating ACP into outpatient clinical practice, especially in patients over 65 years old. Recent changes in federal health policies, such as the annual Medicare physical, have increased the need for primary care ACP delivery tools (Nicholas and Hall 2011), especially because ACP delivery may be included in future evaluations of quality of care (Curtis 2011).

Recent rise in public ACP awareness has stimulated development of grassroots education efforts including National Health Care Decisions Day (NHDD), the One-Slide Project, and the Conversation Project. These focus on patient stories about dying, instead of protocols and population-based quality improvement. Yet, these stories have rarely translated into health-system ACP implementation (Marchand *et al.* 2006), indicating a disconnect between patient experiences and clinical practice; widespread clinical uptake of above ACP strategies into meaningful medical care has not occurred (Wilkinson *et al.* 2007). What is now needed is discourse-based investigation of ACP applications in order to understand and work towards enacting clinical application of grass-roots-based approaches.

While there has been some research on communication in the palliative care setting and among terminally ill patients (e.g. Steihauser *et al.* 2000; Drought and Koenig 2002; Chapelle *et al.* 2006; Gramling and Gramling 2012), there is limited linguistic research about ACP communication outside of the hospital or specialist environment and when death is not immanent. The little research that does exist on ACP discourse focuses on content, abstracting out commonly occurring themes or noting contrasts between patient and provider perspectives on medical interventions (Drought 2000; Hiltunen *et al.* 1999; Baughman *et al.* 2014). This literature pays little attention to the actual details of language, however. Although it provides insight into ACP themes, it cannot give guidance about best language practices for conducting ACP discussions.

Bioethics literature has also recognized the need for more discussion of patients' engagement with ACP, suggesting that current ACP processes and investigation do not capture the multifaceted manner in which patients and families make end-of-life decisions (Drought and Koenig 2002; Chapelle *et al.* 2006). Even mainstream medical journals, e.g. the *Journal of the American Medical Association (JAMA)*, have asserted that the medical field lacks understanding about what patients, providers, and families view as valuable in end-of-life planning, and that methods allowing identification of diverse perspectives must be employed to improve communication about end-of-life (Steihauser *et al.* 2000). Researching details of the language people spontaneously use when substantively discussing ACP, and particularly when narrating previous or prospective ACP experiences and discussions, can provide a foundation for much-needed investigation about discursive ACP strategies within the outpatient clinical environment.

3. Methods

The study consisted of four patient focus groups and one physician group, each with five participants. In this paper we focus on the patient groups. All participants were recruited from a primary-care practice at a large US Midwest

University Hospital. Because improving ACP completion rates necessitates starting discussions early on, in the primary care setting we sought a general (not disease-specific) population. Institutional Review Board conditions required that patients not divulge details about their health.²

Participants ranged in age from between 50 and 80 years old. In order to account for possible ethnic differences in approaches to ACP, two focus groups were of African-American participants and two of White participants, the two major ethnic groups in the local area. Ethnicity was not found to correlate with language use.

Participants knew they would be discussing ACP and that their input would be used to develop better ACP practices. Participants were provided with ACP educational information and a set of sample questions based on the Health Values Questionnaire (Karel *et al.* 2004); patient participants also watched a video about ACP. After these materials were presented, facilitators initiated discussion by asking general questions about any prior discussions they had had about ACP. Participants were then asked their opinions of each sample question (see Appendix for these). Rather than address the sample questions, however, participants developed their own topic trajectories. In these trajectories, narratives spontaneously emerged.

All sessions were recorded and transcribed. Stretches of talk that explicitly mentioned death, dying, or incapacitation to make decisions were then identified, and we examined their linguistic form. This examination revealed that virtually all explicit talk of dying or incapacitation was articulated through either narrative or reported speech – which we refer to as *constructed dialogue*. Therefore, the analysis focuses on these two features.³

4. A discourse analytic approach: Constructed dialogue and narrative

Following Labov (1972), we define narrative as a set of clauses that express chronological events, such that if the order of clauses were reversed, the order of events would be reversed. In this

sense, narrative conforms more or less to the lay definition of *story*.⁴ Telling a narrative opens up a new frame within conversation – a *storyworld* in which the narrated events occur. Narrative helps speakers organize and understand their experiences (e.g. Labov and Fanshell 1977; Bruner 1986; Johnstone 1990); thus, it is a crucial linguistic form for coming to terms with difficult events, past or future.

The first kind of storyworld in our data was *loved ones' end-of-life* storyworlds, where speakers narrated situations of a loved one dying, with or without a plan of care. Past experiences of a loved one's death play an important role in people's thinking about their own future, thus it is not surprising that ACP discussions include a fair amount of such narratives. Equally prominent, however, are hypothetical discussion narratives, in which participants narrate how they might discuss their end-of-life wishes with a loved one. While past-event narratives are useful tools to help people come to terms with *past* events, hypothetical narratives are important for thinking through the *future* experiences (discussions and plan implementation) that ACP encourages.

In the narratives in question, talk of death frequently occurred through the linguistic device of *constructed dialogue* (Tannen 1989) – dialogue that reports what someone has said or would say. Constructed dialogue also occurred outside of the narrative format, embedded instead in conversational talk.

Constructed dialogue dramatizes an event and increases involvement (Tannen 1989), thereby evaluating key features of the narrated events as important (Labov 1972). Constructed dialogue can distance the narrator from what is being said (Clark and Gerrig 1990; Schely-Newman 2009) and help to set up various positions (Davies and Harré 1990) and alignments (Goffman 1981) for characters within a narrative, as well as for the narrator. For example, speakers may systematically alternate between using direct or indirect discourse to report the speech of doctors vs. patients (Hamilton 1998; Cheshire and Ziebland 2005) or the speech of characters that the narrator evaluates negatively or positively (Schiffrin 1996).

Following Clark and Gerrig (1990), Hamilton argues that the doctor-character's direct discourse distances the narrator from the doctor's utterances, thereby – particularly in narratives that portray doctors negatively – providing an air of objectivity that 'help[s] doctors incriminate themselves' (Hamilton 1998: 63) (See also Holt 2000).

Hamilton further remarks that divergent dialogue choices for doctors and patients highlight the status differential between doctors and patients. They can also help *create* the categories 'doctor' and 'patient', position story characters within these categories, and highlight the different relationships of healthcare providers and patients to medical treatments.

Status distinctions can also be invoked through a higher or lower quantity of constructed dialogue for different characters (Cheshire and Ziebland 2005; Schely-Newman 2009). Constructed dialogue may also be used to articulate conflicting views that a narrator holds (Myers 1999; Schely-Newman 2009) or that exist within a community (Modan 2007). The dramatizing effect of constructed dialogue separates the ideas or topics at hand from the narrator and attaches them to a character in the storyworld. As Schely-Newman explains: 'the animation of other people's words allows the interviewees a flexible distance from the events they report in order to critically assess them' (Schely-Newman (2009: 191–192).

We argue that such critical distance allows a narrator to more easily engage with difficult topics like incapacitation and death – likely one reason why constructed dialogue occurs so frequently in ACP discussions. It is also not surprising to see constructed dialogue within the hypothetical narratives in our data; Myers finds that hypothetical constructed dialogue is frequently used in what he calls 'thought experiments' and that it 'enables participants to enact tensions in their own thinking and to deal with opposition between possible views' (Myers 1999: 571).

5. Hypothetical narration

In the following hypothetical storyworld, the speaker focuses on her *lack* of planning for death

and her discomfort with the topic, which we can see both topically, through explicit assertions of feeling awkward, and structurally, through halting speech and false starts. However, when she does bring up planning for the end of life, she uses constructed dialogue. (In the excerpts below we use **bold and underline** to draw attention to the specific utterances of interest. Additionally, /????/ signals unintelligible speech, and [...] signals ellipsed text.)

I sort of feel very awkward because I have been so busy living life that I don't think about what if. I mean, I have – and it's not to say that I have not seen all aspects of illnesses personally for myself and others [...]. I don't let those control my life. I do /????/ and to do and go on. And I feel awkward simply because I know that these are real issues here. They're real things. And at my age, I should be perhaps addressing them more, but I have never really put any real sense of of what's going to happen to me tomorrow, next year. I just never have, you know, because I just feel that um. You know, well, I just think that I am so busy living. I am so busy living it. And um. I am so- I have such a passion and such a love affair with life, but that's not realistic in some aspects either because I don't have any details, you know. I, you know, **I may briefly say something to my daughters one day, I will no longer be here.** But we don't sit down and discuss things this way, and it- and this is why I feel another disadvantage because while I do- you know, I feel that way because you know, I look and I'm looking at all of these questions. [...] They're legitimate questions, you know. Ah, but I know that I'm so busy just – when I see the words living, life meaning, I mean, they're hitting me in so many ways. But those are the things I'm in love with. And I'm not thinking on anything else because I know my day will come, you know when I would- I know- I would think now that I'm not fearful, you know. You know from dying, I fear the dying process, but I don't fear dying. So you know, this is where I am. I am not looking at the papers and what will my doctors all know, saying, **'This is what I want you to do for me.'** And this is what I need to perhaps look into.

The speaker here expresses her focus on life and hesitation to plan for death. Yet she also asserts that ACP is an important topic that she needs to address, and, as we can see in the bolded/ underlined utterances, constructed dialogue helps her make this assertion.

In both cases of constructed dialogue, the utterance referencing what the speaker says she *should* be doing follows a phrase describing what she is *not* doing. First, she asserts that she does not have any details for an advance care plan. She then engages the idea of planning, however, with the constructed utterance, *'I may briefly say something to my daughters one day', 'I will no longer be here.'* In the next utterance she returns to her lack of planning with *'But we don't sit down and discuss things this way.'* Sandwiched between these two negative-polarity sentences, the constructed dialogue highlights the contrast between what the speaker asserts she *should* do and what she describes herself as *actually* doing (or, more accurately, *not* doing). While the highlighting of this contrast drives home the point in the topic sentence of the turn, *'I feel very awkward'*, at the same time it has provided a hypothetical storyworld in which the speaker imagines engaging her daughters in ACP discussions. Thus, constructed dialogue opens a window into a way out of the awkwardness.

The second instance of constructed dialogue is embedded within a larger negative polarity utterance that describes the speaker's lack of action regarding ACP: *'I am not looking at the papers and what will my doctors all know, saying this is what I want you to do for me.'* Labov (1972) remarks that negation, by setting up a contrast to expectations, brings the negated proposition into the discourse at hand, making it part of the landscape of what is being discussed. Thus, the utterance, *'I'm not looking at the papers [...] and saying, this is what I want you to do for me'*, opens up a possible storyworld where the speaker *does* say to her doctors, *'This is what I want you to do for me'*. This constructed dialogue dramatizes and therefore highlights the hypothetical storyworld with its possibilities for ACP discussion. The speaker then reinforces the possibilities opened up by this storyworld with her next utterance: *'And this is what I need perhaps to look into'*. While of course we do not know if this conversation actually spurred the speaker to have an ACP discussion with her daughters or healthcare providers, constructed dialogue here may help lay the groundwork for this speaker's talking to her daughters

by opening up a storyworld in which the speaker envisions and performs such conversations.

6. Narratives of loved ones

Participants who engaged explicitly with end-of-life shared two characteristics. First, they stated they had previously talked about their wishes with loved ones. Thus, mentioning previous participation in ACP talk seems to work as a stepping stone to explicitly engaging the topic in the current conversation. Second, these speakers discussed experiences of seeing loved ones in the terminal stages of life. It stands to reason that direct experience with a loved one dying provides knowledge from which to develop one's own plan (cf. Chappelle *et al.* 2006). However, since it is not clear whether having had such experiences correlates with telling narratives about them, we cannot make claims about the effect of past experiences. What we *can* say is that, since narrations of loved ones' last days so frequently served as a jumping-off point for discussing one's own views, telling such narratives may help people reason through and articulate feelings about, and plans for, their own death and dying.

Loved ones' narratives share with hypothetical narratives the use of constructed dialogue as an organizational device:

Well my sister is a diabetic and she lived alone and she knew that she had kidney problems. And I went with her to her kidney doctor
and he said
'you know, you're almost ready for dialysis'
 and she said
'I filled out the paper that said I will never have that.'
It's my time to go, I'm going.'
 And um,
 so when it came time, um,
he tried to talk her into it
 and she said 'No.'
 My daughter was the power of attorney for healthcare.
And he talked to her and said
 'You know, your aunt needs this'
And she said,
 'This is her wish'

This and other narratives of planning – or lack thereof – are fundamentally narratives

of *discussion* – or lack thereof – in which the protagonist's speech contrasts with that of a doctor or family member who wants them to do something against their wishes. The contrast of the two parties is highlighted by exact, or almost exact, repetitions of quotative phrases (underlined below); the parallelism of these phrases sets off the contrast of the quotes that follow:

and he said
 'you know, you're almost ready for dialysis'
and she said
 'I filled out the paper that said I will never have that.'

Choices about direct or indirect discourse also play an important narrative role. In this first section of the narrative, the speaker's sister's authoritative stance *vis-à-vis* her doctor is reinforced structurally by the sister-figure's matching of the doctor's direct discourse (cf. Cheshire and Ziebland 2005).

In the next section, the aunt's decisive stance is dramatized with direct discourse, whereas the doctor's losing perspective is simply summarized:

so when it came time, um,
he tried to talk her into it
 and she said, 'No.'

In addition to direct vs. indirect discourse, such contrasts can also be highlighted through contrasting quotative phrases. The contrast between the doctor's and the aunt's perspectives is reinforced in the following sequence, where the speaker's daughter is aligned with the sister through the matching of quotative phrases and the distinction of these phrases from the phrase that introduces the doctor's utterance ('*and she said*' vs. '*and said*'). The two women are also aligned through their discursively aligned desires: the niece wants for her aunt what the aunt herself wants.

So when it came time, um,
 he tried to talk her into it
And she said, 'No.'
 My daughter was the power of attorney for health-care.
 And he talked to her
and said
 'You know, your aunt needs this'
And she said,
 'this is her wish'

Where quotative matching aligns the patient and the niece above, in other narratives matched quotative phrases highlight the contrast between different positions. The logic here is that the pattern of repetition set up by the quotatives is interrupted by the shift in stance evidenced in the constructed dialogue that follows. This disjunction serves as an evaluative device to highlight the contrast:

We have a situation-
and then
the case where my father-in-law chose
um
to really di-
not discuss medical care or any of the treatments
uh
even though he was very ill.
And so we decided that we would not put our children
through the anguish or the confusion or frustration
that the remaining family members would have to
decide what
what to do about them.
Like **he wouldn't discuss the will.**
He wouldn't discuss anything with death.
Funeral home.
And um after that
that was a real motivator for us to uh get our house
in order.
We just said
'We're not going to let the kids sit here and just decide
stuff like this.'
But he just absolutely refused
Uh
And his attitude was the hell with it.
And he just said 'you know
do whatever you want.
Bury me anywhere.
You know
funeral –
I don't care.'

Here, the father-in-law's decision not to make any decisions is first mirrored discursively through his lack of speech (cf. Schiffrin 1996): '*He wouldn't discuss the will. He wouldn't discuss anything with death.*' His inaction is first contrasted with the direct-discourse portrayal of the family's stance: '*We just said, "We're not going to let the kids sit here and just decide stuff like this."*' In other words, the contrast in stance is created structurally through the contrast of no constructed dialogue with direct discourse. Next, the contrast is reinforced through the

pairing of quotatives that introduce contrasting stances: '***We just said** "We're not going to let the kids sit here and just decide stuff like this"*' and '***And he just said** "You know do whatever you want."*'

The same pattern can be seen below, where the quotative phrases '*I said Annie*', '*She said Mom*', '*I said Annie*' set off the contrast of views between a speaker's daughter and herself:

I had told my daughter who's the power of attorney.
I said Annie.
if I
if I end up like [a neighbor who has Alzheimer's]
put me someplace that they'll keep me warm
keep me fed
take care of me.
Don't come to visit because –
She said Mom.
You're crazy.
I said Annie.
That devastated that family because they were there
all the time to take care of her.

Because these contrast-highlighting devices help the speakers argue their point of view, they work as evaluative devices to help evaluate the other parties' views as problematic.

7. Conclusion: Laminating selves

By using constructed dialogue in past-event and hypothetical narratives, speakers laminate a storyworld onto the conversation-at-hand in which they are distanced from a state of sickness or incapacitation. Rather than immediately jumping in to discuss their own choices about end-of-life care, speakers 'get their feet wet' by narrating the stories of others, or hypothesizing about what they might tell a loved one.

The constructed dialogue that animates the participants' discourse promotes agency (cf. Schiffrin 1996). Additionally, it creates spaces for cushioning difficult information by articulating such information through the mouths of other characters. This is especially the case for direct discourse – which, as we saw, starkly dramatizes the agentive and decisive stances of protagonists – but indirect speech also provides some agency (Vasquez and Urzúa 2009).

In the stories we have analyzed, narrators wield the choices afforded by constructed dialogue – differential patterns of direct vs. indirect discourse, repetition or contrast of quotative phrases – to explicitly or implicitly evaluate certain points of view as preferred. Additionally, speakers use these features to align themselves with certain storyworld characters – generally, characters who have decisive opinions about end-of-life care and are pro-active in making those opinions known – or they oppose themselves to characters who refuse to engage the topic. In the case of hypothetical narratives, speakers narrate *themselves* as strong, pro-active, and responsible.

The dramatizing and distancing effects of constructed dialogue allow tellers to engage with end-of-life scenarios without getting too close. This is in line with Myers's observation that speakers often use hypothetical constructed dialogue when grappling with contradictory beliefs or behaviors; with hypothetical constructed dialogue, 'participants [could] portray positions they might have had in the past, and might have in the future, without endorsing them in the present' (Myers 1999: 583). Additionally, narrating an ACP discussion may serve as a rehearsal for actually having such a discussion (cf. Simmons and LeCouteur 2011).

A key feature of these storyworlds is that they are primarily about *talk*, and secondarily about dying. Such storyworlds thus embed the frame of incapacity that ACP anticipates, within a frame in which the protagonists are strong, decisive, and proactive about engaging and planning for the prospect of death.⁵ This dual frame structure and the consequent dual subject position that it sets up enable one to engage end-of-life from a position of strength and competence, rather than one of discomfort and fear.

With this analysis, we hope to have lessened the lacuna in the literature about what effective ACP talk can look like, and to contribute in some small way to protocols for navigating ACP discussions in empowering ways. While it is not clear that effective communication in focus groups is the same as what works in a clinical consultation, and while we still know little about the extent to which discussing ACP translates

into putting a plan into place, analysis of the details of ACP communication suggests some possibilities for how providers might approach ACP with their patients and what approaches might be fruitfully evaluated through systematic investigation in a clinical study.

Specifically, providers might ask patients to narrate any experiences they have had with loved ones dying; in the absence of such experiences, providers might put together a packet of stories of others' experiences for patients to read in preparation for an ACP discussion. Additionally, providers might open an ACP discussion by asking questions such as, 'How might you start a conversation with your [spouse, siblings, children, closest friend] about your wishes when you're nearing the end of life? What would you want them to know?' By opening up storyworlds that provide both engagement with and distance from the end-of-life scenario, such questions may provide both patients and providers with better tools to navigate and complete Advance Care Planning.

Appendix: Sample questions

1. What does living well mean to you?
2. What gives your life meaning?
3. What fears or worries do you have about your medical care or your disease?
4. What sustains you when you face serious challenges in life?
5. What makes your life good right now?
6. Can you imagine a time where life would be so unbearable that you would not want medical treatments to keep you alive longer?

Notes

1. Details about POLST can be found at www.the-conversationproject.org
2. We have conglomerate information on health status of each focus group, but this is not linked to individual patients.
3. Because this is a qualitative study we do not focus on the amount of narrative or constructed dialogue; what is important to us is how these forms

correlate with explicit talk of dying. It is worth noting, however, that the features in question were equally prominent across ethnic groups, and about half of the participants told narratives.

4. Because the term *narrative* is not operationalized in other studies on ACP narrative, it is unclear whether other researchers are examining only narratives in this narrow sense, or conversation in general.
5. Note that these storyworlds are different from the practice of patients discussing their values as a prelude to discussing ACP. Discussing one's general value system does not create the same pro-active subject position, since it does not cast the narrator as taking any decisive steps to let others know of his/her wishes. Similarly, discussing one's values does not engage the idea of death as explicitly as narrating what one might tell a loved one about one's last wishes.

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