

Shared decision making and the use of a patient decision aid in advanced serious illness: provider and patient perspectives

Jacqueline Jones PhD RN,* Carolyn Nowels MSPH,† Jean S. Kutner MD MSPH‡ and Daniel D. Matlock MD MPH§**

*Associate Professor, College of Nursing, University of Colorado, Aurora, CO, †Senior Health Research Specialist, ‡Professor, §Assistant Professor, School of Medicine, University of Colorado, Aurora, CO and **Research Group Member, Colorado Cardiovascular Outcomes Research Group, Denver, CO, USA

Correspondence

Jacqueline Jones PhD, RN
Associate Professor
College of Nursing
University of Colorado Anschutz
Medical campus
13120 E 19th Ave
Campus Box C288-19
Aurora
CO 80045
USA
E-mail: jacqueline.jones@ucdenver.edu

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Abstract

Objective Patients with advanced serious illness face many complex decisions. Patient decision aids (PtDAs) can help with complex decision making but are underutilized. This study assessed barriers and facilitators to the use of a PtDA designed for serious illness.

Methods Providers and patients were asked about their experiences in making decisions around serious illness and their opinions towards the PtDA. Seven focus groups were digitally recorded, transcribed and analysed using a general qualitative inductive method.

Results Domain 1 – clinical context within which the PtDA would be utilized including three themes: (1a) role: PtDA might compete with the physician's role; (1b) logistics: it was unclear when and how such a PtDA should be implemented; and (1c) meaning: what it will mean to the patient if the physician recommends viewing of this PtDA. Domain 2 – broader global context: (2a) death-denying culture; and (2b) physician concerns that the PtDA was biased towards palliative care.

Conclusion Physicians' concerns were rooted in deeper concerns about palliative care and a death-denying culture. Patients were more open to using the PtDA than physicians, suggesting 'it's never too early'.

Practice Implications PtDAs for serious illness can maximize early opportunities for goals of care conversations and shared decision making.

Introduction

Advance care planning is a process that occurs over time through multiple discussions rather

than a one-time event.¹ Advance care planning, which can be used to prepare and teach patients and surrogates how to make informed future medical decisions when they arise, is

applicable across all health settings.² Patients with advanced serious illness and their families face an array of complicated and value-laden decisions about many therapies including chemotherapy, mechanical ventilation, artificial nutrition and hydration, hospitalization and hospice enrolment. Shared decision making (SDM) is a model that facilitates guided communication between clinical provider and patient as biographical expert in partnership to a mutually acceptable decision for care.³ Despite provider goals for patient-centred care and SDM,⁷ patients with advanced serious illness are generally not well informed about the available care options or their prognosis.^{4,5} A host of research suggests that patients want their doctors to discuss prognosis, advance directives and end-of-life care,^{6–8} this is not happening as often as it should.^{7,8}

Patient decision aids (PtDAs) have emerged as an effective intervention to improve SDM.⁸ A Cochrane review of 86 randomized trials involving 20 209 participants concluded that PtDAs improve knowledge and satisfaction, and reduce decisional conflict and regret.⁹ Likewise, PtDAs are nearly always rated acceptable or helpful by patients.⁹ Traditional PtDAs typically focus on single event decisions¹⁰ and are not as applicable to patients and families dealing with the challenges of advanced and terminal illnesses; indeed, the Cochrane review explicitly excluded 'end-of-life decisions'. Proponents for the use of decision aids to assist patients with advanced or terminal illness are increasing.¹¹ The impetus for SDM lies in patient–provider partnerships for the process of sharing information and coming to an agreed preferential decision concordant with patients' values and beliefs. The PtDA as a visual tool can map out advantages and disadvantages to available potentially acceptable care options for deliberation by both patient and provider.^{3,11}

Aims

Despite evidence demonstrating their effectiveness, implementation of PtDAs into real-world

clinical settings has been limited, with well-documented barriers to implementation.³ We anticipated that a PtDA focused on decisions related to advanced or terminal illness may have additional barriers to implementation, particularly physician discomfort with the content and topic area. To explore barriers and facilitators to adoption, implementation and maintenance, we conducted a qualitative descriptive study¹² of physicians who frequently care for patients with advanced or terminal illness. We then contextualized these concerns with a primary care patient population.

Methods

Study design

An emergent qualitative descriptive research design provides an opportunity to explore social or professional phenomena, to gain deeper understanding of complex decisions or underlying assumptions/concerns.¹² It also allows the research data to inform and build depth to subsequent qualitative data collection. The primary purpose of our study was to explore providers' opinions about adoption, implementation and maintenance of a PtDA for patients and families facing serious illness.

Decision aid

The PtDA, *Looking Ahead: Choices for medical care when you're seriously ill*, which consists of a 37 min DVD and companion 51 page booklet, was developed by The Informed Medical Decisions Foundation and Health Dialog to encourage conversations, advance care planning and patient-centred decision making related to advanced illness.¹³ Given the breadth of potential diagnoses and decisions that could have been included in the PtDA, a purposeful decision was made to focus on more global issues such as palliative care, advance care planning, hospice and proxy decision-makers. It uses narrative to portray a host of patient and provider perspectives. Specific decisions

such as use of artificial nutrition and hydration, mechanical ventilation and cardiopulmonary resuscitation were not addressed in detail given limitations on the length of the PtDA and the recognition that each of these specific decisions would require a full PtDA to address. The PtDA is proprietary and now distributed by Health Dialog.¹³

To study how to best implement this PtDA in real-world settings we used the RE-AIM implementation framework.¹⁴ The framework helps understand pragmatic elements of recruitment and participation in an intervention (Reach), the impact of the intervention on outcomes meaningful to patients (Effectiveness), likelihood of staff or setting perceived feasibility and uptake (Adoption), process modifications or adaptations that would be needed (Implementation) and the extent to which an intervention can become part of routine practice (Maintenance). The first two components of the evaluation framework reach and effectiveness (RE) of the PtDA were assessed among patients and their decision-makers from the inpatient palliative care service at University of Colorado Hospital through a pilot randomized controlled trial (RCT).¹⁵ Reach was quantified as the proportion and representativeness of the target population of individuals willing to participate, while the effectiveness was measured by impact outcomes of decision conflict and knowledge.¹⁵

For this study, we were guided by RE-AIM domains 'AIM' to ensure the group interviews would help us get at barriers and facilitators of future adoption, implementation and maintenance of the decision aid.¹⁴ We chose focus groups as our primary method of data collection for this study because it allows for exploration of diverse views in a group setting. It also allows for the deeper probing of unwritten norms related to the context of practice. In the context of an emergent design, we initially conducted four focus groups, including primary care physicians as well as oncologists, hospitalists and other intensivists within the health-care system. As the study progressed, we added a fifth focus group of palliative care providers

(physicians and an advanced practice nurse) and two patient focus groups to gain a deeper insight into the themes that were arising from the physician focus groups. The patient groups included both chronically ill and well patients in direct response to opinions and values expressed by providers about patients with serious illness and subsequently, opinions and values expressed by patients with chronic illness about well patients.

Sampling and recruitment

Our study used snowball sampling¹⁶ to identify 'providers' and then 'patients' with experiences and understandings of serious advanced illness. We recruited non-palliative care physicians from four Denver area hospital systems through a key contact in each setting. The contact emailed potential participants in his/her organization explaining the purpose of the study; all who responded were invited to attend the focus group that best fit their schedule. Providers from a large teaching hospital palliative care team were invited to a separate focus group to explore their opinions about the PtDA as well as their thoughts regarding the non-palliative care providers' perspectives on the PtDA. The five provider focus groups were conducted during the months of April and May 2010.

Based on findings from the provider focus groups, the research team decided to further explore issues raised by the non-palliative care providers through focus groups of patients (both chronically ill and well) recruited through an academic internal medicine clinic using fliers and a self-referral strategy. Patients were 18 years of age and older and English-speaking. Stable outpatients with a range from younger, healthier people to older people with multimorbidity (eg COPD, hypertension and diabetes) were purposefully selected. The two patient focus groups took place from October to December 2010.

All focus group participants received a meal and gift card in appreciation of their participation. All groups were facilitated by experienced qualitative researchers, digitally recorded and

transcribed by a professional transcriptionist. Transcripts were checked for accuracy and uploaded to ATLAS.ti® version 6.2 for organization, coding and analysis.

This study was approved by the Colorado Multiple Institutional Review Board. Informed consent was obtained from all participants.

Data collection

Participants were shown the PtDA (video and booklet) at commencement of the focus group and then asked questions about its relevance. The focus group interview guides were developed and refined through an iterative team process with broad, open-ended questions to elicit in-depth discussion of the PtDA. RE-AIM domains included reaction to the potential use of a PtDA for patients and families facing serious illness and how the PtDA might fit within patient health-care delivery. The data relating to participants’ opinions about the specific PtDA (such as length and design) have been previously analysed and reported to the developer. The analysis for the current study focuses on the broader themes related to the multiple contexts in which providers and patients view and may potentially use this type of PtDA.

Analysis

We analysed the provider and patient focus group data using an inductive, team-based, low-inference interpretive approach to explore patterns and preliminary themes in the data.^{16,17} One member of the team (DM) reviewed a subset of transcripts, meeting regularly with the primary coder (CN) to resolve coding issues and to create the codebook. Other team members (JK and JJ) reviewed a sample of transcripts and met with the entire team to discuss emerging themes as well as discrepancies, disconfirming and confirming cases and alternative explanations.^{16,17} The remainder of the transcripts were coded using an iterative approach of immersion, team consultation, exploration of within-case and cross-case variation, visual mapping and re-

immersion to create a richer contextualization of the complexity of the landscape of this PtDA through our participants’ language. We presented the results to several external groups, including provider researchers, a national meeting of the funding agency and a local palliative care research meeting to further refine analytic interpretation in a wider context.

Results

A total of forty-one individuals participated in the focus groups. These included both palliative care (*n* = 4) and non-palliative care (*n* = 25) providers and patients (*n* = 12) (Table 1). All provider participants were physicians except for a single advance practice nurse who was part of the palliative care provider focus group (Table 2). For clarity, the term provider will be used throughout.

Across the seven focus groups (providers and patients), findings coalesced around two main

Table 1 Participant demographics

	Providers <i>n</i> = 29	Patients <i>n</i> = 12
Age		
<35 years	41%	Mean = 66.4
36–45	38%	Range = 28–96
46–55	14%	
56–65	7%	
Gender		
Female	41%	66%
Race/ethnicity		
White	86%	100%
Education level		
Post-college		66%
College grad		25%
HS grad		9%
Years in practice		
1–5 years	52%	
6–10 years	14%	
11–20 years	17%	
21+ years	17%	
Primary practice setting		
Academic	79%	
Number of patient deaths, in previous year		
<10	24%	
11–20	38%	
>20	38%	

Table 2 Provider specialty

Specialty	<i>n</i>
Internal medicine	18*
Palliative medicine	4 [†]
Geriatrics	2
Medical Oncology	2
Cardiology	1
Pulmonary/Critical Care	1
Surgery	1
Total	29

*Both hospitalist and internal medicine outpatient-physicians.

[†]One advanced practice nurse in palliative care.

domains related to the introduction and use of the PtDA. The first domain relates to the clinical context in which providers receive their medical training and practice medicine, and includes several subdomains: the first domain: (a) roles: provider preparation/training for their roles in patient/family decisions when facing serious illness; (b) logistics: the process of these decision-making discussions with patients and families (who, when and how); and (c) meaning: the critical issue of contextual meaning of these patient/family decisions – what they signify to patients/families and to providers. The second domain, global context, finds its roots in societal beliefs and norms around death and dying. This larger context impacted providers' views of their roles in late-life decision making, both professionally and personally, as well as the patients' perspective about this point in their life trajectory. Table 3 illustrates the contrasting perspectives across palliative and non-palliative care providers and patients.

Provider perspective on clinical context: Role, logistics, meaning

Role

Non-palliative care providers spoke of how decision making related to serious illness impacted their practice, whether based in inpatient or outpatient settings. Some expressed concern about their roles in caring for patients with advanced illness, citing their perception that their job emphasizes life-prolonging care, as well as a perceived dearth of formal prepa-

ratory training in communication related to advanced serious illness. Non-palliative care providers also agreed with the sentiment offered by one provider that 'providers are not very good at admitting defeat'. The introduction of a PtDA into this already ambiguous territory (between different worldviews) raised criticism of the PtDA and its goal because it ran counter to what providers called the existing medical cultural role of cure or fail. Non-palliative care providers saw the PtDA as devaluing the role of the provider, as they felt they were already delivering palliative care to their patients and yet were not receiving acknowledgement of their contributions. The PtDA was labelled by several as an 'easy out', a way to avoid spending the time necessary to discuss this important topic.

Logistics

There was a lack of consensus around the logistics of beginning these complicated conversations with patients: who should be using the PtDA, when and where (inpatient vs. outpatient) the PtDA would be appropriate, if at all. Some hospitalists expressed frustration that the discussion was 'left' to them when they felt it should have been addressed much earlier in the course of illness. Additionally, the amount of time required for these complex discussions was seen as a major obstacle. For others the PtDA seemed 'like a conversation starter for somebody to chew on for a while'. Palliative care providers endorsed use of the PtDA as a routine part of 'general health maintenance', at an earlier or 'upstream' time point, seeing it as less appropriate for acute crises where patients and families may not have the ability to concentrate on a PtDA such as this. They further suggested using the PtDA in a group setting where a facilitator could answer questions and move the process along.

Meaning

All providers voiced their concerns about patients' perceptions of underlying/unspoken messages from clinicians, that is what does it mean to patients when providers 'hand' them a

Table 3 Comparison across groups of key issues related to the decision aid

	Non-Palliative Care Providers	Palliative care providers	Patients
Clinical context: Meaning What does it mean when provider introduces decision aid?	I agree it can set the wrong tone where you're almost like handing them this [decision aid] and... they probably think, 'Oh my God! My doc thinks I'm dying.' And maybe they are, but... that's not the impression you necessarily want to [give]... We're often as hospitalists forced to have the conversation with the person even though we're just meeting them or it's something that we think should have been maybe addressed a long time ago. We're often kind of the ones who end up talking to people about it because it comes down to us.	People just don't like to talk about it whether it's a patient or a doctor. I mean, but you still have to, you know, so... I mean yeah, I think probably a lot of those are just reflecting their own fears or their own on their patients. I think the context of it [decision aid being introduced] really makes a difference... we're just way too downstream. And I think the further you go upstream, the less frightening it is	It's just normal things [illness and eventual death] that happen. Why should you hide it? And it [decision aid] shouldn't just be for people that are elderly! ... maybe if I'm not ill... maybe that would be the time to say 'Have you thought about this...?' I mean I don't think it's something you can bring up too soon... I think earlier would be better.
Clinical Context: Logistics When should the decision aid be introduced?	it's [discussion of serious/advanced illness] so misunderstood because... I think it's still in American culture if we're not doing something curative or life sustaining then we're giving up.	..it's [discussion of serious/advanced illness] still an uncomfortable thing even though it's our profession and we should be discussing this with all of our patients regardless, you know, doctors still have their own issues and I think those things in itself can just be threatening too.	[it becomes easier over time] If you have been associated with a terminal illness in somebody, you get pretty immune to talking about what's going on. I mean you've been there. You've done it. And then when it comes your turn, at least you've got that experience to back you up. Which is helpful I think.

PtDA? Many non-palliative care providers expressed concern that the PtDA could be viewed negatively by patients or their families and might reduce and adversely impact the provider's role in the decision process. They were afraid it could be seen as a 'death message', abandonment and/or 'giving up' on the part of the provider. Palliative care providers felt the meaning of the PtDA and conversation to patients varied depending on the setting and timing of the conversation ('upstream' vs. 'downstream'). If the PtDA was used in the context of usual visits or usual care (upstream), patients would view it as a normal part of care, 'not scary' rather than a frightening 'death message (downstream)'. Palliative care providers saw the shared decision model inherent in the PtDA as potentially 'threatening' to some non-palliative care providers, as it may create activated patients who may or may not share similar values as providers regarding, for example life prolongation. One provider stated:

There's a sense of threat to many physicians that we talk about activated patients where they can make the decisions especially that may be out of a different value or different treatment goal... the reality is...it's easier to substitute our own values and goals...it's inherently threatening in some way to promote the shared decisional model.

Provider perspectives: global context

The society, within which both patients and providers live, health-care systems exist and medical care is delivered, comprises an overarching context, part of the intricate tapestry of both patient and provider worlds. Non-palliative care providers spoke of what we labelled the 'death taboo' prevalent in society – how we as a nation do not openly discuss end of life.

...people don't want to talk about... death... people just don't like to talk about it whether it's a patient or a doctor. But you still have to... I think probably a lot of [providers] are just reflecting their own fears or their own on their patients.

It is in the midst of this death-denying milieu that providers found themselves attempting to negotiate a universally difficult topic. They reflected this death-denying culture through the challenges and discomfort they expressed during the groups. Many spoke in euphemisms and seemed to struggle in finding the appropriate words to use. There were frequent pauses, avoidance or hesitation with wording as the discussion progressed; a common language or professional discourse related to death as part of living was not evident. In contrast, palliative care providers spoke of the misperceptions of non-palliative care providers around the role of providing palliative care, indicating that the term 'palliative care' itself is not well understood and may lead to misunderstandings and barriers. The palliative care providers also acknowledged the prevalent social norm of avoiding discussion of end of life. They admitted their own discomfort at times in raising this issue with patients, seeing it as 'difficult for any American' including doctors themselves.

The patients and their families don't want to talk about this. Even if doctors try to talk about it, they get rebuffed pretty frequently by the patient and their loved ones and we see that at least as often where the physicians haven't made the effort. And I think that that combination then is deadly.

Patient perspectives of clinical context: Logistics, meaning

Logistics

The patient focus groups (including chronically ill and healthy patients of varying ages) confirmed (1) a belief that the PtDA was not only useful but that providers should introduce the PtDA sooner rather than later with patients/families as well as (2) a perception that PtDAs increase patient empowerment with regard to self-advocacy in their interactions with providers. Patients were aware of the limited time providers have for these discussions and offered alternate strategies for reaching the public with the PtDAs (e.g. assisted living

centres, churches and other established social groups). Patients also spoke of serious illness and death as part of the ‘human condition’. They emphasized that ‘we all need to do this’ (learn about the decisions related to serious illness) and determined that ‘having a better informed patient and making those decisions when you are well is the right thing’. Patients saw the PtDA as a vehicle for beginning an important discussion and raising people’s awareness of the topic. They indicated that they expected their providers to ‘step up’ and begin these important discussions rather than ‘dodging’ challenging questions as they had experienced providers doing in the past.

In contrast to the findings from the non-palliative care providers, patient participants felt strongly that the topic ‘applies to the masses’, that it is crucial to learn about available options, to be well informed and serve as an advocate for oneself and/or family members. Interestingly, several participants had been asked about their personal code status prior to recent medical procedures and were caught ‘off guard’ as they were not prepared to state their wishes on the spot. These experiences reinforced their views that people should receive the PtDA earlier rather than later – they reiterated that it is ‘never too early’ and that the topic should be raised ‘...when [people] are not sick’.

Meaning

Patients emphasized the importance of ‘opening the door to conversation’ on this topic. They interwove humour with a ‘normalizing’ focus, indicating that while it might be at times an uncomfortable topic, it was nonetheless highly important. They did confirm providers’ fears in the context of a death-denying society that if the provider simply handed the PtDA to patients without explaining that the individual was not being singled out, rather than that everyone receives the materials, many would think ‘it would mean I was dying’. They did, however, voice concern at the ‘half-baked’ answers providers offered. Some patients advocated ‘the more they bring it out [discussion of

serious/advanced illness] the better off you are’. Patients expressed strong opinions about how society ‘hides’ the topic of end of life, and the urgent need for everyone to be exposed to the concepts and decisions discussed in the PtDA, regardless of age or illness status, resonant with the ‘upstream’ concept raised by the palliative care providers.

...people of all ages should see that [decision aid]. I don’t think it should just be [people] our ages. I mean, young people should see this so they know...

Discussion and conclusion

Discussion

Participants in this study taught us several important things about using decision aids for patients with advanced serious illness. Patients reiterated the importance of this decision aid and argued that this is something that all patients should approach. They were open to the introduction of the PtDA and had views on factors that would influence their overall experience with providers including provider training or reluctance to spend the time. Providers’ opinions varied based on their opinions about palliative care, and this highlights that further work is needed to explore the tensions between provider personal and professional goals and shared decision-making roles with patients and families. Reach and effectiveness of the PtDA were assessed in a prior pilot randomized controlled study of inpatient palliative care patients and their decision-makers.¹⁵ Our prior study suggested that inpatients and decision-makers wanted this PtDA earlier. Our primary care patients validated the main thematic findings from that study¹⁵ stating that the PtDA was highly acceptable and should be given early in the course of illness. What we know now is that near the end of life is likely too late.¹⁵ However, whether it should be given during a state of stability by a PCP, or during the time of diagnosis by a specialist or hospital team is unanswered. Also, whether this could

be introduced by a physician, nurse or social worker also remains to be seen. This particular decision aid was not designed for a clinical encounter – a 37-min video would logistically never fit within a clinical encounter as designed. Ideally, the design of the tool needs to fit the context while ‘preparing’ the patient and their surrogates to participate with their provider in making the ‘best possible in-the-moment decisions’ when they arise in the future.¹ This PtDA has previously been shown to influence ‘how participants would handle future discussions with physicians’, by prompting the type of questions they asked, promoting a more proactive role and assertive involvement in care decisions.²⁴

An earlier review of patients’ preferences for involvement in medical decision making identified that perceived disease significance and interactions with health professionals influence the style of the decision-making process.¹⁸ Our study included women and supports the contention that providers should not stereotype decision style based on ethnicity, gender or ground options based solely on their own professional/specialist worldview. SDM requires a more tailored approach¹⁹ in which a PtDA, such as in this study, can be a catalyst for an effective shared decision-making process in serious illness if they remain open to the conversation in the first place and include patients to the degree to which they desire, yet simultaneously recognize patient diversity including the desire not to be an active partner in SDM.

The major barrier to adoption of the PtDA seen in our work is the prevalence of a death-denying culture.²⁰ The ‘death-denying’ findings seen in the microcosm of this United States study echo larger discussions that have occurred on a macrolevel.²⁰ Perhaps the starkest example recently was related to the Affordable Care Act’s initial discussions around reimbursing clinicians for end-of-life discussions. This was quickly labelled ‘death panels’ by opponents of the act. The ‘death panel’ label was immediately effective and that language was removed from the final version of the law providing strong evidence that the cul-

tural death denial is a contemporary truth. Thus, it should not be surprising that one of the largest barriers to implementation of a PtDA related to serious illness is the cultural context into which it is being implemented. Even the palliative care movement has embraced the cultural death denial by arguing that palliative care is not about death. Some of this death denial may be related to the rapid advances that modern medicine has seen over the last 50 years where death has been systematically institutionalized and is now seen as a failure of medicine rather than a reality of life.²⁰ This parallels the movement in the UK for example with the relinquishment of the Liverpool Care Pathway²¹ for more tailored and individualized approaches to end-of-life decision support.

This study illuminates some of the challenges and highlights how future work in patient-centred care and shared decision making is needed for a PTDA such as this to be adopted. Even within this context, specialist and generalist providers are not on the same page either about palliative care, serious advanced illness and death. Our data suggests certain boundaries may exist around cure and death depending on which sphere of medical practice providers belong to.

Some commentators believe patients do not want to be informed,⁴ but this opinion is not based on evidence and the preponderance of evidence suggests that patients do want to be informed.⁹ Where this study distinguishes itself from clinician focused studies, such as SUPPORT,⁵ is by bringing the focus on patients. Patients (or providers) do not want to talk about advanced care planning at the end of life if they have not talked about the context of such preferences when the patient was in better health.²² But, if they have talked about end-of-life preferences earlier, does that facilitate a different and subsequent advanced care planning discussion? Advance care planning is now argued as a multistep process that should start with diagnosis and be revisited over time.^{1,22–24} Providers, however, may not wish to approach patients in fear of being seen as a

failure to cure or wanting to maintain hope.²⁴ Patients in turn may 'think I am dying' if they are individually targeted by their provider rather than being asked in the context of education about palliative care as part of a welcome to Medicare or Medicare wellness examination each year. Despite these immediate fears, patients who were well and those with advanced serious illness in our study were open to starting a conversation, if the context within which it is presented is clear and revisited.

Future work is needed to determine provider styles of shared decision making depending on personal approach to end-of-life medicine as well as professional specialty practice. Our data suggest the key barrier to implementation of this PtDA is doctor buy-in. Doctors saying things like 'I would never show that to my patients' and patients saying things like 'I would want my doctor to introduce this' is precisely the conundrum to implementation. It is culture change that is the key doctors need to be open to the fact that it is okay to tell their patients these things. Through the Respecting Choices programme, La Crosse, Wisconsin, USA, have made detailed discussions about end of life the norm. It is reported that 96 percentage of those who die have completed Advance Directives or given clear instructions of what ought to be done in the event of serious illness which in turn has meaningfully reduced medical expenditures.^{22,25} Key recommendations from that successful initiative include allowing enough time to train health professionals and discussion facilitators in end-of-life communication; to establish advance care planning as a routine way to offer care using integrated systems; and to change the way many older adults associate written Advance Directives and 'living wills' as the only way to preserve autonomy rather than a discussion based approach that evolves over time with change in the patient need, health or social status. A medical utilization argument combined with medical cultural humility and a patient-centred outcome approach to communication²³ could assist doctors with buy-in reservations.

A broad public health campaign educating the public on end-of-life choices may make it easier for providers to have individual discussions with patients about their choices, which has seen success in the UK.²⁶ Many clinicians remain concerned about educating patients about palliative care let alone helping them with their complex and often uncertain decisions despite innovative decision-making technologies for preparing for advance care planning and end-of-life discussions.⁹ The Institute of Medicine (IOM) report, *Dying in America*,²² places emphasis on changing the way health professionals are educated to include: interprofessional collaboration models of education as palliative care is oriented to team culture; to improve and enhance palliative care within curricula and Board certification exams across all health disciplines; and to enhance communication skills in health professional programmes.

Strengths and limitations

This study has several strengths. First, this decision aid was developed through a rigorous evidence-based process and was not focused on a single illness; therefore, it has a broader applicability and addresses concepts that are important for all patients. Second, an emergent design allowed us to test out subculture perspectives of palliative and non-palliative care providers and further contextualize our findings with both ill and well patients. The study is limited by the dominance of White and well-educated patient participants where cultural and ethnic diversity may offer alternate contextual nuances related to the use of a PtDA. While two focus groups included patients, the patients who participated in the focus groups may also have very different views than the patients being considered in the examples provided by providers. Patients willing to participate in this study may be more open to discussing palliative care than patients in general. Provider participants were largely from academic settings, and providers who are community-based from private systems or rural

settings may have different concerns and attitudes to the place of a patient decision aid in advanced illness. Finally, our study only included palliative care providers from one palliative care team and therefore may have missed some of the mixed opinions in the field about the place of PtDAs in general versus individually tailored communication strategies.

Conclusion

Our study found that physicians' concerns about using this PtDA were rooted in deeper concerns about palliative care and decision making in serious illness in general. The breadth of challenges perceived by participants to general acceptance of the PtDA is coloured by a death-denying culture and topic avoidance within the United States as confirmed by the newly released IOM report, *Dying in America*. There are differences across provider opinions based on clinical specialty and past experience with palliative care. The logistics of implementing a PtDA for SDM with patients experiencing serious illness are also influenced by the context of the provider and perceived utility and timing of such a conversation. Some providers could anticipate the utility of having patients review the PtDA prior to a clinic visit. Others were conflicted by the inappropriate nature of their own setting such as in hospital use was perceived to be too late and primary care too time-limited to be feasible. Patients were more open to using the PtDA and saw it as an opportunity for conversation particularly when they were healthy. Patients did, however, want to be prepared for the conversation through normalizing the regularity of the topic at routine clinic visits.

Practice implications

PtDA are perceived to be useful by patients to begin conversations with providers around future complex decisions in advanced serious illness. Providers need to reconsider how best to augment their communication practices with a PtDA to maximize early opportunities

for preparing patients for shared decision making. Formal medical and health education to confront and reframe our death-denying culture within a new palliative care landscape is needed to support both provider and patient challenging conversations in serious illness.

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Conflict of Interest

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