

# SUPPORTING EVIDENCE FOR THE DEVELOPMENT OF THE HOSPICE DECISION AID

Last Updated:

January 1, 2019

Table of Contents

Introduction ..... 3

Development Team ..... 4

Development Process ..... 5

    Overview ..... 5

    Ottawa Decision Support Framework (ODSF) ..... 5

        I. Needs Assessment ..... 5

        II. Decision Aid Development ..... 6

Paper Patient Decision Aid Development and Feedback Table ..... 8

Video Patient Decision Aid Development and Feedback Table ..... 14

**REFERENCES** ..... 19

## Introduction

Hospice is underutilized. Despite the documented benefits of hospice, less than 2 million people utilize hospice services annually,<sup>1</sup> more than one third of all hospice users spend less than 7 days receiving care,<sup>1</sup> and approximately only 40% of eligible Medicare beneficiaries die enrolled in hospice. In other words, almost two-thirds of eligible patients do not benefit from the documented advantages of hospice care. Of note, racial and ethnic minority patients account for only 15% of all hospice users,<sup>1,2</sup> and when they are enrolled, they spend less time in hospice services than white patients, averaging fewer than seven days enrolled in hospice care.<sup>3,4</sup> Further, the percentage of the oldest old utilizing hospice services has plateaued over the last several years with little more 50% enrolling in hospice.<sup>5</sup> The reasons for underutilization are complex but include knowledge barriers and misunderstandings about hospice care by both physicians and patients,<sup>6-8</sup> cultural beliefs about death,<sup>9-11</sup> lower health literacy in older adults and minorities,<sup>12-14</sup> physician gatekeeping and late referral,<sup>7</sup> and disparities in access to quality healthcare.<sup>6,9,10,15</sup>

Although hospice has existed for more than 40 years, many people and even some physicians do not fully understand hospice care.<sup>16</sup> For example, many patients misunderstand the payment mechanism for hospice and incorrectly believe they are unable to afford hospice care, despite the fact that most payers cover hospice services. Some believe that enrolling in hospice requires institutionalization, despite evidence that 80% of hospice care occurs at home, and those enrolled in hospice are more likely to die at home.<sup>1,16,17</sup> For some, hospice conveys the message of “giving up”, even though evidence suggests that hospice enrollees and their loved ones report a sense of hope, relief, and improved quality of life.<sup>18-20</sup> Finally, people report concerns that hospice hastens death, despite evidence that hospice is not associated with shorter survival and in some cases hospice enrollees live longer than those seeking curative treatments.<sup>19,21-24</sup> To understand how to address these misconceptions, we performed a qualitative needs assessment with patients, caregivers and healthcare providers. We found, in addition to the aforementioned misunderstandings, that hospice is often not presented as an option for patients until death is imminent, and caregivers are consequently unaware of the potential support provided by hospice. Caregivers expressed regret for not knowing about or enrolling in hospice earlier in the disease course of their loved ones. The patient decision aid (PtDA) being evaluated in this study is designed specifically to address these misperceptions of hospice care.

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## Development Process

### Overview

We used elements of shared decision making by offering choice in a method that highlights patient values. A feature that distinguishes our DA from an information pamphlet is that in addition to information, the DA supports patients in clarifying their values to determine what is important to them. We incorporated elements of behavior change theory (self-efficacy, relative risks for benefits etc.) to help guide patients towards decision making. We created a paper and video using an iterative approach incorporating feedback from development team members (see Table 1), from patients and caregivers (see Table 2), from a variety of hospice providers (see Table 3) and expert advisors (see Table 4). We gave careful consideration to health literacy and numeracy in the DA development. We followed the recommendations for clear communication which ensured both the paper and video versions are written at a 5<sup>th</sup> grade level (Using Flesch-Kincaid analytics available in Microsoft word).<sup>25-27</sup>

The guiding methodology in the development of the decision aid were the Ottawa Decision Support Framework (ODSF)<sup>28,29</sup> and the International Patient Decision Aid Standards (IPDAS).<sup>29-31</sup>

### Ottawa Decision Support Framework (ODSF)

The Ottawa Decision Support Framework (ODSF) is an evidence-based, practical, mid-range theory for guiding patients making health or social decisions. It uses a three-step process to: assess client and practitioner determinants of decisions to identify decision support needs; provide decision support tailored to client needs; and evaluate the decision making process and outcomes.<sup>17,28</sup>

#### I. Needs Assessment

To understand how we could address these misconceptions and how they may ultimately influence hospice utilization, we performed a qualitative needs assessment. The purpose of the needs assessment was to determine what barriers prevent patients and families from using hospice services, how to move hospice enrollment upstream in disease trajectory to allow patients and families maximum time to benefit from services, and to develop interventions that may increase hospice use.

We conduct a series of focus groups (n=11) and semi-structured interviews (n=6) with patients diagnosed with advanced illness, informal caregivers of hospice patients, and providers working in hospice and/or with patients with advanced illness. A total of 63 individuals participated in focus groups or semi-structured interviews. We interviewed 4 patients, 32 caregivers and 27 providers (e.g. social workers, nurses, chaplains) regarding their perceptions of participating in hospice. In the preliminary analyses, we found that all participant groups describe misunderstandings and myths regarding hospice care consistent with those cited in the literature. Additionally, we learned that timing of introduction and initiating of hospice care was a major theme across all participants. Hospice is often presented as an option only when death is imminent. As a result, caregivers expressed regret for not being aware of or enrolling their loved ones in hospice earlier in the disease course.

Additionally, we conducted a rigorous environmental scan of the current patient decision aids (PtDAs) available for hospice care and found only 7 PtDAs that even mentioned hospice as a potential secondary treatment option for people with end stage heart failure, cancer or kidney disease. These PtDAs fail to adequately explain the nuances of hospice care as primary treatment option.<sup>32</sup> Further, they have limited reach to the population of aging adults resulting from the specificity of diagnosis associated with each. To address this, we used an iterative, user-centered approach with multi-stakeholder input, and guided by the Ottawa Decision Support Framework<sup>33</sup> and by the International Patient Decision Aid Standards<sup>29,31</sup> to develop a hospice PtDA for anyone facing end-of-life decisions regardless of diagnosis.

## II. Decision Aid Development

Based on our needs assessment and environmental scan, we developed an initial draft of the paper tool which underwent a process of iterative testing to assure accuracy, readability and lack of bias including:

### **Interviews with Patients, Caregivers and Health Providers**

Interviews with patients, caregivers, and clinicians and experts in end of life care and shared decision making. They were then asked to review prototypes of the PtDAs and provide constructive, candid feedback along with areas for improvement. Iterative process, refer to feedback log. A log of all feedback provided by patients, caregivers, clinicians and experts was maintained to track the iterative process.

### **Prototype Development and Testing**

- Drafting structure and content – initial content for the prototype came from focus groups and interviews conducted with patients, informal caregivers and hospice providers. We incorporated revisions provided by the experts. These early drafts were presented to patients, informal caregivers and hospice providers.
- Design and construction of interactive website – The infographic was used as the template for the website with the addition of patient video clips and interactive questions.
- Video production – The Development Team drafted a script that went through several iterations before filming began. We chose to have a Cardiologist specializing in end stage heart failure be the primary narrator for the video and another member of the Development Team provided more detailed information. Consenting patients were asked a series of questions and that video footage was honed into the vignettes included in the video and on the website.
- Field testing - reviewed by expert patient panel and expert clinician panel. Once all addressable changes were incorporated and saturation of feedback was achieved, we finalized the versions of the tools.

**Translation-Pending**

**Revision Policy**

The Development Team will annually review the literature and update the tools as needed.

Paper Patient Decision Aid Development and Feedback Table

Date	Source	Suggestion/Comment	Response/Outcome/Changes
05/31/16	Development Team	<ul style="list-style-type: none"> <li>• First paper version of DA developed</li> </ul>	<ul style="list-style-type: none"> <li>• Focus groups and interview participants were supportive of the need for a hospice Specific PtDA. Suggested focusing on what hospice is, why people need it, where it is administered and how one pays for hospice.</li> </ul>
05/31/16-10/04/16	Development Team	<ul style="list-style-type: none"> <li>• 7 iterations of paper decision focusing on content identified as important in focus groups/interviews and graphic design.</li> </ul>	<ul style="list-style-type: none"> <li>•</li> </ul>
02/11/16	Patient Advisory Committee	<ul style="list-style-type: none"> <li>• Advisors were supportive of the overall goal of the decision aid and suggested a video format would be helpful</li> <li>• Panel suggested more clarity on hospice eligibility requirements</li> <li>• Be more explicit on where patients can receive hospice care</li> </ul>	<ul style="list-style-type: none"> <li>• We agree and plan to develop a video when the content paper tool is finalized.</li> <li>• We added a page specific to eligibility criteria.</li> <li>• We will add a page to the tool that explains where hospice care is administered and where patients can receive hospice care.</li> </ul>

Paper Patient Decision Aid Development and Feedback Table Continued

Date	Source	Suggestion/Comment	Response/Outcomes/Changes
10/13/16	Patient Advisory Committee	<ul style="list-style-type: none"> <li>• There was much conversation of the language used in the tool. Many did not like the term “curative care” and suggested saying medical care or life-sustaining care instead.</li> <li>• The group felt we did not clearly differentiate or explain differences between hospice and palliative care</li> <li>• Create strong contrast between text and background, e.g., black text on white background. The light blue text on pp. 1-2 will be hard for people with visual impairments/low vision to read.</li> </ul>	<ul style="list-style-type: none"> <li>• We agree that picking the right language is critical. We decided to keep the term “curative care” because hospice is in fact medical care and some argue (and some literature suggests) that hospice is also life sustaining.</li> <li>• We are working on clarifying the difference between hospice and palliative care</li> <li>• Great comment. We are working hard to redo the graphics and lay out of the tool incorporating this feedback</li> </ul>

Supporting Evidence For The Development of the Hospice Decision Aid

Date	Source	Suggestion/Comment	Response/Outcome/Changes
01/12/17	Hospice Providers Focus Group	<ul style="list-style-type: none"> <li>• “Just present the fact”-providers felt the DA should only present the facts about hospice and not provide any inducing/prejudicial information for or against hospice</li> <li>• Be explicit about the Medicare hospice benefit.</li> </ul>	<ul style="list-style-type: none"> <li>• We agree and have spent great effort to development a tool that is neutral yet presents an accurate representation of hospice care.</li> <li>• We felt the finances of hospice to be critically important so we added an entire page discussing payment in the tool.</li> </ul>
02/06/17	Patient & Caregiver Focus Group	<ul style="list-style-type: none"> <li>• We asked this group about the necessity of cultural tailoring and resounding people felt tailoring is a bad idea.</li> <li>• Add more about financials.</li> <li>• Add more about how hospice is not a place.</li> <li>• Hospice is not where people go to die.</li> </ul>	<ul style="list-style-type: none"> <li>• We agree that cultural tailoring may not be the best approach for this type of decision aid.</li> <li>• We plan to re-design the page on how hospice is paid for. It is clear this is important given feedback from multiple sources.</li> <li>• We added a statement that says, : “80% of hospice care is delivered in the patients’ home.”<sup>1</sup></li> </ul>
02/06/17	Patient & Caregiver Focus Group	<ul style="list-style-type: none"> <li>• We like the values clarification questions at end of tool.</li> <li>• There should info in the tool about morphine.</li> <li>• Why is there no information about Right to Die and Organ Donation?</li> </ul>	<ul style="list-style-type: none"> <li>• We feel discussing morphine is outside of the scope of the tool. The purpose of the tool is to provide accurate info on hospice in order to facilitate a more detailed discussion between patients/providers.</li> <li>• Right to Die laws and organ donation are not issues associated with decision making around hospice care. As such they will not be discussed in the tool.</li> </ul>
03/21/17	University of Colo. PC Works Progress Group	<ul style="list-style-type: none"> <li>• Recommended to design for dissemination.</li> <li>• Is the tool appropriate for all cultures, religions, and differing groups?</li> </ul>	<ul style="list-style-type: none"> <li>• It is unclear when the best time along a disease trajectory to introduce hospice. We plan to explore this issue in grant/efficacy testing.</li> <li>• We explicitly designed a tool that was neutral and did not favor any particular group.</li> </ul>

Supporting Evidence For The Development of the Hospice Decision Aid

Date	Source	Suggestion/Comment	Response/Outcome/Changes
		<ul style="list-style-type: none"> <li>• End-user design issues. Are doctors going to use this?</li> <li>• There should be more info on the specific costs of services offered by hospice.</li> </ul>	<p>Feedback we received in focus groups was that tailoring, of any sort, was offensive.</p> <ul style="list-style-type: none"> <li>• We hope that doctors will use this tool. We are trying to strike a balance between patient forward and provider forward design. We will evaluate implementation issues in future grant work.</li> <li>• We feel this level of detail about specific costs is outside the scope of the tool.</li> </ul>
03/22/17	VA Advisory Board	<ul style="list-style-type: none"> <li>• There needs to be a Veteran specific decision aid. Good to explain what hospice is for Veterans, where it occurs, who decides. Be clear up front because there's so much confusion.</li> <li>• Emphasize that Veterans have a choice about hospice.</li> <li>• Due to experiences in the military, Veterans are sensitive to being "sold" on things. Make sure decision aid tool reflects this, very biased right now with the quotes and fonts.</li> </ul>	<ul style="list-style-type: none"> <li>• We agree. We hope to write a grant to specifically tailor the tool for use in the VA.</li> <li>• This was great feedback. We plan to change the current tool to address some of this issues. We added the language, "the choice/decision is YOURS" to almost every page of the tool. The goal is to emphasize the choice and promote patient centered care.</li> </ul>
04/26/17	Hospice Providers Focus Group	<ul style="list-style-type: none"> <li>• Providers recommended a more detailed discussion of the "morphine myth."</li> </ul>	<ul style="list-style-type: none"> <li>• We agree this is a key barrier to hospice enrollment but feel a detailed description of morphine use is outside of the scope of the tool.</li> </ul>
05/30/17	Development Team	<ul style="list-style-type: none"> <li>• First version of the video script developed.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>SEE BELOW FOR VIDEO FEEDBACK TABLE</b></li> </ul>

Supporting Evidence For The Development of the Hospice Decision Aid

02/21/18	Older Veteran Engagement Team (OVET)	<ul style="list-style-type: none"> <li>• One of the keystones of Hospice is quality of life. Statement to add:             <ul style="list-style-type: none"> <li>○ What do <u>you</u> want the remaining time you have to look like?</li> <li>○ What do I enjoy doing?</li> </ul> </li> <li>• Decision aid needs to be very explicit about what home hospice looks like.</li> <li>• Be real and very concrete about level and intensity of care required, especially of caregivers. Decision aid needs to include considerations for caregivers.</li> </ul>	<ul style="list-style-type: none"> <li>• A question addressing this concern was added to values clarification page.</li> <li>• We feel a detailed description of the specific services provided in the home is slightly outside the scope of the tool. The idea is that the tool would facilitate such conversations between patient/provider.</li> <li>• This is great feedback. We will revise some of the language in the tool to be more explicit in the fact that hospice is there to support caregivers as they provide care.</li> </ul>
02/04/19	Copy Editor	<ul style="list-style-type: none"> <li>• Change: "the goals of palliative care is" to "goals of palliative care <b>are</b>"</li> <li>• Add commas: "Hospice does not cure disease, but provides pain and symptom management, along with emotional and spiritual support to loved ones"</li> <li>• Add comma: "Medicare, Medicaid, and private..."</li> <li>• Add comma: "pain management, symptom control, and emotional and spiritual support."</li> <li>• Add comma: "certified nursing assistants, and physicians".</li> </ul>	<ul style="list-style-type: none"> <li>• All edits suggested by the copy editor were made.</li> </ul>

Supporting Evidence For The Development of the Hospice Decision Aid

		<ul style="list-style-type: none"><li>• Should be 24-hour (but the 24 hours on the previous page without the hyphen are correct).</li></ul>	
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## Supporting Evidence For The Development of the Hospice Decision Aid

### Video Patient Decision Aid Development and Feedback Table

Date	Source	Suggestion/Comment	Response/Outcome/Changes
03/08/18-05/02/18	Development Team	<ul style="list-style-type: none"> <li>We iterated the script 9 times internal before finalizing a version for filming</li> </ul>	<ul style="list-style-type: none"> <li></li> </ul>
05/09/18	Development Team	<ul style="list-style-type: none"> <li>Filming of video begins</li> </ul>	<ul style="list-style-type: none"> <li></li> </ul>
08/02/18	Development Team	<ul style="list-style-type: none"> <li>Filming complete</li> </ul>	<ul style="list-style-type: none"> <li>When filmed five patient narratives and one MD to serve as narrator for the film.</li> </ul>
05/25/18	Development Team	<ul style="list-style-type: none"> <li>First version of video complete</li> </ul>	<ul style="list-style-type: none"> <li>Video is 24 minutes in length. This is too long we will make edits to cut and make shorter</li> </ul>
06/25/18	Experts in SDM and PtDAs	<ul style="list-style-type: none"> <li>Video is lacking clarity on what the “choice” is regarding hospice.</li> <li>Patient clips feel disjointed from the content of video.</li> </ul>	<ul style="list-style-type: none"> <li>GREAT comment. We plan to reorganize the film to highlight that hospice is a treatment choice. We will also add more sections stating that hospice may not be the right choice for each patient.</li> <li>Great comment again. We will reorganize the patient clips so that they directly relate to the content being discussed in the video.</li> </ul>

Date	Source	Suggestion/Comment	Response/Outcome/Changes
08/09/18	Development Team	<ul style="list-style-type: none"> <li>• Tighten up transitions (some fade out while talking, some fade in while talking)</li> <li>• Some of the patient clips are too choppy. Need to figure out how to splice less...</li> <li>• What is the point of the clips? Shorten clips – full patient stores on the website is a great idea</li> <li>• Maybe just four sections in the middle part: 1) Spiritual and Emotional support; 2) Voluneers; 3) respite (if we keep); 4) Grief/bereavement support</li> <li>• Consider putting “What hospice care does not provide” “ earlier in the video next to the “what is palliative care and hospice”;</li> <li>• We could ask ourselves if the FAQ is needed for the video?</li> <li>• Consider left justification with indentations rather than centering.</li> </ul>	<ul style="list-style-type: none"> <li>• All transitions were smoothed out</li> <li>• All patient clips were smoothed out</li> <li>• Patient clips were matched to video content</li> <li>• Shorten all patient clips to shorten video</li> <li>• We removed the FAQs from the video. They are presented in the paper tool and removing them shortens the video</li> </ul>
09/20/18	UC Health Geriatricians	<ul style="list-style-type: none"> <li>• Could there be a brief outline - "We're going to talk about today</li> <li>• In the what's not provided section:</li> <li>• Could add in "around the clock caregiver (health aids not available 24 hours)" again.</li> </ul>	<ul style="list-style-type: none"> <li>• We previously had an outline and did not think it felt right. We will keep as is.</li> <li>• Will add to end summary</li> <li>• Detailed discussions of nursing homes is outside the scope of the video.</li> <li>• We feel that we make it clear that hospice is for end of life.</li> </ul>

Supporting Evidence For The Development of the Hospice Decision Aid

		<ul style="list-style-type: none"> <li>• When discussing respite in care center, would also state " or nursing home"</li> <li>• Perhaps not enough references to death. Count how many times you reference death, end of life period; as the person nears the end of their life? It may be fewer than you think. Ensure that comfort care is what you mean, and not a euphemism for death.</li> <li>• Check the eligibility language. This was confusing. May need to describe or define eligibility or describe "as long as you are eligible, which includes continuing to decline</li> <li>• In Channing's story "transitioned over" - euphemism for death "room to herself" - too concrete</li> <li>• Should the additional questions be at the end vs the beginning? If there is an outline up front, probably ok to have the questions at the end.</li> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>• We will address eligibility and make sure it is clear</li> <li>• The patient stories are a critical part of this video. There stories are their truths and we will NOT edit them in anyway</li> <li>• Will keep the questions at the end as we feel the video builds to helping viewers thing about these questions</li> <li>•</li> </ul>
09/20/18	Experts from the Denver Hospice	<ul style="list-style-type: none"> <li>• Attending physician – patients have a right to still their doc - Grey area in the doc part. There will be a change in what you may see and the hospice team will help you sort that out.</li> </ul>	<ul style="list-style-type: none"> <li>• We appreciate this comment however we have found in speaking to patients the most if not all must forfeit seeing their current doctors, especially any specialist, when they enter hospice. In the DA we say things like, "you MAY have to stop seeing SOME of your</li> </ul>

Supporting Evidence For The Development of the Hospice Decision Aid

		<ul style="list-style-type: none"> <li>• Most hospices provide support groups – not correct</li> <li>• Some hospices have an inpatient care center” – because most don’t.</li> <li>• Recertification: not always a visit.</li> <li>• Please re-emphasize that hospices do not provide round the clock care.</li> <li>• Add info about hospice in Assisted Living Facility to the hospice-</li> </ul>	<p>doctors” in an effort to find balance between these tensions.</p> <ul style="list-style-type: none"> <li>• Even though it is true that some hospices o not have bereavement services they do refer patients to other hospice that do over services therefore we will leave this language in the tool.</li> <li>• Yes but this is a general discussion guide. The statement that some hospices have inpatient</li> <li>• Great feedback however we feel our language shows that you are not kicked off hospice care after 6 months and that the recertification is not hard</li> <li>• Thank you for this comment. We added another section to the video explicitly stating that hospice does not provide round the clock care.</li> <li>• ALF is outside the scope of the video. Video is meant to be a general discussion generator. We mention you can get hospice is a variety of nursing home care settings.</li> </ul>
12/05/18	Development Team	<ul style="list-style-type: none"> <li>• There still needs to be more discussion/comments to make this decision aid-y</li> </ul>	<ul style="list-style-type: none"> <li>• We reviewed the IPDAS criteria and decided to add a benefits and drawbacks section to the video to greater highlight the decision to be made</li> </ul>
02/12/19	Focus Group Participants	<ul style="list-style-type: none"> <li>• Loved the overall look and feel of video</li> <li>• Patient clips at richness and realness</li> <li>• Like the diversity of people in video</li> </ul>	<ul style="list-style-type: none"> <li>•</li> </ul>

Supporting Evidence For The Development of the Hospice Decision Aid

		<ul style="list-style-type: none"> <li>• Felt like it explain hospice well</li> <li>• Loved the section on how to pay for hospice</li> </ul>	
03/26/19	University of Colo. PC Works Progress Group	<ul style="list-style-type: none"> <li>• People had issues with the word “curative”. Alternative suggestions included:               <ul style="list-style-type: none"> <li>○ “life prolonging therapies”</li> <li>○ “disease focused therapies”</li> <li>○ “Disease modifying therapies”</li> <li>○ “when curative therapies are no longer helping you in your _____”</li> </ul> </li> <li>• People suggested including a definitions page at the beginning of the video and in pamphlet about terms being used</li> <li>• There were concerns regarding the white writing on the green background being difficult to read</li> <li>• There was a desire to have audio playing over the title pages in the video</li> <li>• There were questions about whether or not we were able to talk to people who had chosen NOT to use hospice when making the video and pamphlet</li> <li>• People really want a sheet with the video link to give out to people so that they could stream it</li> <li>• People want the video up!</li> </ul>	<ul style="list-style-type: none"> <li>• We appreciate this comment and we did have a difficult time deciding how the address this issue in both the paper and the video tools. Ultimately, we will continue to use curative because it is a basic literacy appropriate term. We are currently pilot testing the tools and we will consider modifying language in the next iteration of the tools based on feedback from the pilot study.</li> <li>• We piloted putting definitions in the beginning of the tools but people found it distracting and preferred for them to be at the end.</li> <li>• This is a good comment. We will test other color configurations for future iterations.</li> <li>• We found that having audio over the title slides was distracting so we will leave as is.</li> <li>• Unfortunately we were not able to talk to decliners despite our sincere effort to find some. This is a key weakness and we will continue to work to find decliners.</li> <li>• We are planning to include information about streaming the video in the packets.</li> <li>• Noted. Video is up for general use on our website</li> </ul>

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