

BRIEF

# Cost Information Enhances Shared Decision Making

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Lessons from FAIR Health's Shared Decision-Making Initiative

A FAIR Health Brief, December 10, 2020



## Summary

Shared decision making (SDM) involves patient-clinician communication to decide on tests, treatment and care based on clinical evidence, balancing risks and outcomes with patient preferences and values. To accomplish SDM, evidence-based strategies and patient materials called decision aids (DAs) are often used. SDM shows promise for reducing unnecessary healthcare spending and costs, and for improving decision making without adverse effects on clinical outcomes. It is particularly applicable in scenarios involving preference-sensitive conditions (those for which the clinical evidence does not clearly support one treatment option and the appropriate course of treatment depends on the values or preferences of the patient) and those involving palliative care decisions for serious illness. Despite the evidence of SDM's value, its adoption has not been widespread.

In April 2019, the Board of Directors of The New York Community Trust (The Trust) approved a grant to FAIR Health to implement an 18-month SDM-Palliative Care program. On March 10, 2020, with support from The Trust, FAIR Health launched an [SDM feature](#) with cost information at [fairhealthconsumer.org](http://fairhealthconsumer.org) (FAIR Health Consumer) to aid patients residing in the greater New York metropolitan area who have serious illnesses and are facing palliative care decisions, and their caregivers. Targeting adult patients (18+ years of age) in the greater New York area and New York State who are in palliative care situations and their caregivers, FAIR Health's initiative involved pairing cost information with DAs for a set of palliative care scenarios on FAIR Health's award-winning, free consumer website, FAIR Health Consumer, for the following options: (i) staying on or stopping kidney dialysis for end-stage renal disease, (ii) pursuing different nutrition options when swallowing is difficult and (iii) staying on or removing a breathing machine.

FAIR Health successfully publicized the feature through diverse channels, including social media, digital media and FAIR Health's newsletters, as well as through outreach to organizations and clinical experts who serve palliative care patients and their families. The SDM section on FAIR Health Consumer received over 40,000 unique visitors nationwide in the first six-and-a-half months since it launched.

FAIR Health presents salient program learnings in this brief to help inform current and future shared decision-making initiatives, whether focused on palliative care or other clinical areas. Among the lessons learned:

- **Conversations surrounding cost in palliative care enhance decision making.** Based on conversations with palliative care experts, cost information provides an additional layer to the information presented about clinical treatment options.
- **Utility and value of SDM tools.** Based on the qualitative insights and quantitative results we collected, providers and consumers alike deemed the SDM tools useful and valuable to SDM conversations in palliative care scenarios.
- **Acceptability of the SDM tools and appetite for additional tools.** The acceptability of the SDM tools to both providers and consumers—and an appetite for additional SDM tools—were highlighted by the qualitative and quantitative data we collected over the program period.
- **Provider acceptability of SDM tools is a critical pathway for promoting SDM.** Confirming the literature findings that providers are critical for SDM initiatives, our findings further suggest that clinicians welcome the guidance of SDM tools when having difficult SDM discussions. Early results point to acceptability of DAs among consumers; it nevertheless appears that providers, at least in the palliative care space, are also an important conduit for promoting shared decision making.
- **Need to improve awareness of SDM and patient DAs among providers.** Despite some awareness of SDM as an approach to clinical practice, the idea did not appear to be very familiar among palliative care providers.

## Background

Although patients in the United States shoulder a significant portion of their healthcare costs, research suggests that they may not always receive the care they prefer.<sup>1</sup> Shared decision making (SDM) involves patient-clinician communication to decide on tests, treatment and care based on clinical evidence, balancing risks and outcomes with patient preferences and values.<sup>2</sup> To accomplish SDM, evidence-based strategies and patient materials called decision aids (DAs) are often used.

SDM shows promise for reducing unnecessary spending<sup>3</sup> and healthcare costs,<sup>4</sup> and for improving decision making without an adverse effect on clinical outcomes.<sup>5</sup> SDM has been found to be particularly effective in scenarios involving preference-sensitive conditions (those “for which the clinical evidence does not clearly support one treatment option and the appropriate course of treatment depends on the values or preferences of the patient”<sup>6</sup>) and patients with serious illnesses facing palliative care decisions. Despite the evidence of SDM’s value, its limited adoption may be due to time constraints during clinical encounters, and lack of accord regarding what SDM should comprise and what clinician training is needed regarding how to use DAs in practice when DAs exist.<sup>7</sup>

Dr. Glyn Elwyn and his team at Dartmouth College’s Institute for Health Policy and Clinical Practice developed Option Grid™ patient DAs for various clinical decision-making scenarios and developed additional DAs that account for scenarios in which patients are seriously ill. The DAs allow patients to compare two to three clinical options at once. However, like most DAs, they do not include cost information that would serve to complement the clinical options provided.

## The FAIR Health SDM-Palliative Care Program

To address the need for SDM palliative care tools that offer both clinical and cost information, FAIR Health undertook an 18-month initiative geared for adult patients (18+ years of age) who are in palliative care situations and their caregivers. FAIR Health’s initiative involved pairing cost information with the Option Grid DAs for a set of palliative care scenarios on FAIR Health’s award-winning, free consumer website, FAIR Health Consumer. The palliative care scenarios selected, and therefore the types of patients who were targeted, were: (i) staying on or stopping kidney dialysis for end-stage renal disease, (ii) pursuing different nutrition options when swallowing is difficult and (iii) staying on or removing a breathing machine.

FAIR Health developed corresponding cost information for each of the DA treatment options by analyzing the FAIR Health National Private Insurance Claims (FH NPIC®) dataset. This helped us determine which service codes—including Current Procedural Terminology (CPT®)<sup>8</sup> codes and Healthcare Common

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<sup>1</sup> Brian J. Zikmund-Fisher et al., “Deficits and Variations in Patients’ Experience with Making 9 Common Medical Decisions: The DECISIONS Survey,” *Medical Decision Making* 30, no. 5 (September 2010): 85S-95S, <https://doi.org/10.1177/0272989X10380466>.

<sup>2</sup> “Fact Sheet: Shared Decision Making,” HealthIT.gov National Learning Consortium, December 2013, [https://www.healthit.gov/sites/default/files/nlc\\_shared\\_decision\\_making\\_fact\\_sheet.pdf](https://www.healthit.gov/sites/default/files/nlc_shared_decision_making_fact_sheet.pdf).

<sup>3</sup> Emily Oshima Lee and Ezekiel J. Emanuel, “Shared Decision Making to Improve Care and Reduce Costs,” *New England Journal of Medicine* 368 (January 2013): 6-8, <https://doi.org/10.1056/NEJMp1209500>.

<sup>4</sup> David Arterburn et al., “Introducing Decision Aids at Group Health Was Linked to Sharply Lower Hip and Knee Surgery Rates and Costs,” *Health Affairs* 31, no. 9 (September 2012): 2094-2104, <https://doi.org/10.1377/hlthaff.2011.0686>.

<sup>5</sup> Megan E. Branda et al., “Shared Decision Making for Patients with Type 2 Diabetes: A Randomized Trial in Primary Care,” *BMC Health Services Research* 13, no. 301 (August 2013), <https://doi.org/10.1186/1472-6963-13-301>.

<sup>6</sup> Annette M. O’Connor et al., “Modifying Unwarranted Variations in Health Care: Shared Decision Making Using Patient Decision Aids,” *Health Affairs* 23, no. 2 (October 2004): 63-72, <https://doi.org/10.1377/hlthaff.var.63>.

<sup>7</sup> Fiona Ryan and Susan Cunningham, “Shared Decision Making in Healthcare,” *Faculty Dental Journal* 5, no. 3 (July 2014): 124-127, <https://doi.org/10.1308/204268514X14017784505970>.

<sup>8</sup> CPT © 2020 American Medical Association (AMA). All rights reserved.

Procedure Coding System (HCPCS) codes (which largely denote durable medical equipment and injectable drugs, among other items)—and associated costs would inform the DAs in the new cost results sections.

To assure consumer-friendliness and appeal to clinicians, we solicited and implemented feedback on the DAs and educational content from several palliative care experts, who included:

- A palliative care social worker at a hospital;
- A palliative care physician at a hospital;
- The heads of national and state-based hospice groups;
- The head of a palliative care advocacy group; and
- A nephrologist completing her fellowship in palliative care, affiliated with multiple hospitals.

FAIR Health completed the technical interface development of the DAs on the consumer site and developed educational content on SDM in palliative care decisions to serve as companion pieces to the [SDM feature](#). This included an educational Insurance Basics article<sup>9</sup> that covers information on what patients and caregivers need to know about SDM.

On March 10, 2020, just as the COVID-19 pandemic was beginning to affect the lives of countless individuals worldwide, FAIR Health launched the SDM feature with a press release and multichannel dissemination effort. We promoted the SDM feature through a wide variety of dissemination channels, including a press release, Facebook ads, social media posts, articles and blogs, FAIR Health newsletters and outreach to palliative care providers and organizations such as the CAPC and NHPCO. Notably, outlets such as CNBC, Crain’s Health Pulse and *U.S. News & World Report* all reported on the SDM feature.

## Program Learnings

FAIR Health conducted a program evaluation, which offered a unique opportunity to learn about the impact of the SDM tools on patient/caregiver decision making and to better understand the points in the decision-making process at which they would be most helpful. We collected qualitative and quantitative data over a six-and-a-half-month period. Qualitative methods included conducting key informant interviews/qualitative feedback sessions with palliative care experts. Quantitative methods included calculating usage analytics on social media (e.g., Facebook, Twitter) and website users using digital platforms (e.g., Google Analytics) and collecting feedback from a survey designed by Dr. Elwyn. In addition, we added questions to our existing consumer site survey to capture feedback on the appetite for SDM tools in other medical areas.

### Conversations Including Cost Information Enhance Shared Decision Making

The topic of costs related to palliative care scenarios arose during the qualitative feedback sessions. With respect to the nutrition options DA, one expert indicated, “For this particular arena, cost is a little more important,” and later, “When talking about cost, we try to be very sensitive about how we present cost information, trying to understand the burden of costs for healthcare as opposed to putting a price on something.”

Another palliative care expert opined on palliative care cost conversations:

*“Regarding costs, it’s a little bit of a dance...Palliative care social workers, caregivers—we have feelings about inequalities in the healthcare system...We try not to dangle choices that aren’t feasible, so we try not to make executive decisions for people.”*

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<sup>9</sup> FAIR Health, “Palliative Care and Shared Decision Making,” FH® Insurance Basics, <https://www.fairhealthconsumer.org/insurance-basics/your-costs/palliative-care-shared-decision-making>.

*“We see patients all across the financial spectrum. We have some patients who tell us that cost doesn’t matter, ‘You just tell us the options and we’ll find a way to make it work.’ Whether or not they actually have the money, they want to make it clear that they don’t want me to think about money and want me to tell them all of the options. They like to set the tone at the start. And other families for patients not getting anything not covered at 100 percent—they can’t pay for private supportive care that is expensive. These families know that they don’t have the option and so we generally don’t even talk about that. Families will often bring it up, copays. They worry a lot about being judged about costs, but it makes them practical. They navigate with social workers to get those answers.”*

Moreover, most (83 percent) survey respondents indicated that the cost information on the tools was either “helpful” or “very helpful.” Evidence suggests that cost is quickly becoming an important consideration in palliative care. According to the Center to Advance Palliative Care (CAPC), it was estimated that, across the United States, approximately six million people were in need of palliative care, and approximately 68 percent of Medicare costs are related to patients often associated with palliative care: those struggling with four or more chronic conditions.<sup>10</sup>

### Utility and Value of SDM Tools

Based on the qualitative insights and quantitative results we collected, we observed that providers and consumers alike deemed the SDM tools useful and valuable to SDM conversations in palliative care scenarios. We interviewed six individuals who had diverse roles in healthcare: a nurse practitioner at a supportive cancer care hospital, a nephrologist/palliative care fellow, a supervisor of volunteer services at a hospice, an associate professor of geriatric palliative medicine at an academic medical center, a home hospice social worker and the head of a state-based hospice/palliative care group.

These interviews provided valuable information about the readiness of health professionals to embrace the concept of SDM and the use of tools such as patient DAs. All interviewees had heard the term “shared decision making,” but the comments revealed a hesitancy to comment on a description of the term, suggesting a lack of confidence in being able to say whether or not they understood the concept well enough to comment. The same reaction applied to patient DAs. Only one interviewee confidently attested to direct knowledge of such tools; others reacted as if the idea of using well-designed, accurate comparative information for patients was novel. Nevertheless, there was no obvious negative reaction to the tools. On the contrary, all interviewees were willing to read the content in detail, and provided insightful suggestions for editorial changes. The interviewees could contemplate these tools being useful in two ways: first, to prepare patients and their caregivers for discussions with one or more providers; and second, as tools to stimulate collaborative discussions among providers. However, the interviewees also revealed that such preparatory or collaborative use is rare, and not considered yet to be part of normal workflows in most healthcare organizations. The quote that exemplified this best is: “A lot of people don’t have insight into these interventions...so I think they might be helpful if people were steered towards them.”

Interviews underscored the following themes:

- 1. Awareness, but no direct experience of SDM or of patient DAs.** Despite some awareness of SDM as an approach to clinical practice, the interviewees have no direct experience of SDM, nor are the interviewees strongly supportive. This reaction is common among health professionals. Very few health professionals have more than an awareness of the term, and few have come across high-quality patient DAs.
- 2. Positive appraisals, focused on content, and colored by a reaction that the concept of using comparison tables was novel to them in this context.** The interviewees are generally positive about the tools, and although there are many comments on the content of the tools, there

<sup>10</sup> “Palliative Care Facts and Stats,” Center to Advance Palliative Care, 2014, [https://media.capc.org/filer\\_public/68/bc/68bc93c7-14ad-4741-9830-8691729618d0/capc\\_press-kit.pdf](https://media.capc.org/filer_public/68/bc/68bc93c7-14ad-4741-9830-8691729618d0/capc_press-kit.pdf).

are no examples of overt negative responses. None of the interviewees see the tools as inappropriate for use with patients and others.

In the aggregate, most (83 percent) survey respondents for each of the tools indicated that after using the tools, making a decision was either “easier” or “much easier.” The utility and value of the SDM tools also are underscored by the fact that most respondents to the FAIR Health consumer site survey indicated “yes” in response to the question of whether it would be helpful if the site offered more tools for SDM.

### **Acceptability of the SDM Tools and Appetite for Additional SDM Tools**

The acceptability of the SDM tools to both providers and consumers—and an appetite for additional SDM tools—were highlighted by the qualitative and quantitative data we collected over the program period. A total of 20,800 unique visitors from the greater New York tristate area and 16,000 unique visitors from New York State visited the SDM feature from March 10, 2020, through September 30, 2020 (the close of the grant period).

Additional notable statistics about users of the SDM feature include the following:

- Females compose 75 percent of users, while males compose 25 percent.
- Most users are aged 55 and older, with 39 percent aged 65 and older and 29 percent aged 55-64.
- Most visited tools, in order from most to least visited, were: kidney dialysis, nutrition options and breathing machine.

The qualitative analysis complements the quantitative data and underscores the need for these tools as well as the need for healthcare providers to use these tools with patients and caregivers. In response to the consumer site survey question, “The site currently offers three shared decision-making tools on palliative care. Would it be helpful if the site offered more tools for other medical conditions?,” 64 percent of respondents said “yes.” When asked to elaborate, two comments in particular were enlightening: “The more information the better. Patients don’t always know what to ask. This would help.” Another comment: “Yes! Patients need to be more empowered to navigate their healthcare decision-making. Validated SDM tools would be of great use.”

Comments within the questions to the consumer website survey regarding the SDM tools highlight an appetite for tools that cover additional topics, e.g., cancer and COPD.

### **Provider Acceptability of SDM Tools a Critical Pathway for Promoting SDM**

Confirming the literature findings that providers are critical for SDM initiatives, our findings further suggest that clinicians welcome the guidance of SDM tools when having difficult SDM discussions. Early results point to acceptability of DAs among consumers; it nevertheless appears that providers, at least in the palliative care space, are also important conduits for SDM interventions and tools. Given the clinician-patient nature of SDM discussions, providers should be considered as target audiences for future SDM initiatives that simultaneously target consumers.

The COVID-19 pandemic and its repercussions underscored the importance of making critical medical decisions early on in the process and, ideally, prior to the point of needing to make those decisions. Qualitative feedback sessions with experts also highlighted how palliative care decision making changed during the pandemic. Once confined to palliative care specialists, palliative care decision making largely became the purview of other types of healthcare providers, who were forced by circumstances to make critical decisions concerning life and death. Experts discussed the value of having SDM conversations early on in the decision-making process and suggested offering additional information on code status and CPR for SDM discussions.

In reference to the dialysis tool, one expert said:

*“It would be a tool to refer patients or families to if they had larger questions about dialysis, intubation or ventilation, artificial nutrition or hydration. You could refer them to them in*

*preparation for discussion with a palliative care team. A lot of times we have these big family meetings that they can prepare for and if they know when the meeting is going to be, you can say, 'Oh, look at these tools and see if you have any [questions].'"*

A social worker had this to say about decision making with patients in hospice:

*"When patients come to hospice, the talk is focused on end of life, unfinished business, what is dying like—physically and emotionally. The family tells me what to do. The family guides you as to what they want. With palliative care, you still have options. But there are decisions to be made. Most of the time, most people are open to advance directives. And it's about providing the information they need."*

## Considerations for Communication in Shared Decision Making for Palliative Care

Palliative care, much like other types of medical care, requires special sensitivity around conversations that take place between healthcare teams and patients and their caregivers. During our discussions with palliative care experts, we were exposed to the ways in which palliative care providers approach the topic with their patients sensitively. We were advised to avoid using the term “end of life” when communicating with patients and caregivers because many patients do not think of themselves, or wish to think of themselves, as being at the end of life. Accordingly, we changed the language to “serious illness and chronic illness” to account for this consideration.

## Women as Caregivers

Based on the results from Google Analytics, 75 percent of consumers who access the SDM tools are women. Our findings are corroborated by the literature on caregivers. An estimated 66 percent of caregivers are female.<sup>11</sup> Indeed, women provide the majority of informal care to family members, friends and neighbors in a variety of capacities, including decision maker and advocate.<sup>12</sup> When comparing familial and unpaid caregivers, women may spend up to 50 percent more time providing care than male caregivers.<sup>13</sup> Moreover, women live an average of five years longer than men, leading them in many cases to become caregivers for their spouses.<sup>14</sup> Women compose 70 percent of the paid healthcare workforce.<sup>15</sup> It also has been found that women make 80 percent of all healthcare decisions for their children.<sup>16</sup> The role of the woman as primary caregiver is therefore an important consideration when designing and launching SDM initiatives.

## Conclusion

FAIR Health presents these program learnings with the hope that they will help guide a range of stakeholders—including clinicians and payors—who seek to advance SDM. Conversations about clinical treatment options and costs present an opportunity to empower healthcare consumers and patients to make critical healthcare decisions with their clinicians that not only affect their health but their finances. In

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<sup>11</sup> The National Alliance for Caregiving and AARP, *Caregiving in the U.S 2009*, AARP Research, December 2009, [https://www.aarp.org/research/topics/care/info-2014/caregiving\\_09.html](https://www.aarp.org/research/topics/care/info-2014/caregiving_09.html).

<sup>12</sup> Maryam Navaie-Waliser et al., “When the Caregiver Needs Care: The Plight of Vulnerable Caregivers,” *American Journal of Public Health* 92, no. 3 (March 2002): 409-413, <https://doi.org/10.2105/ajph.92.3.409>.

<sup>13</sup> “Read How IOA Views Aging in America,” Institute on Aging, 2016, <https://www.ioaging.org/aging-in-america#womanliving>.

<sup>14</sup> “Women and Caregiving: Facts and Figures,” National Center on Caregiving at Family Caregiver Alliance, last updated February 2015, <https://www.caregiver.org/women-and-caregiving-facts-and-figures>.

<sup>15</sup> “Women in the Health Workforce,” World Health Organization, March 7, 2018, 12:30-2:00 pm, <https://www.who.int/hrh/events/2018/women-in-health-workforce/en/>.

<sup>16</sup> “General Facts on Women and Job Based Health,” US Department of Labor: Employee Benefits Security Administration, accessed December 2020, <https://www.dol.gov/sites/dolgov/files/EBSA/about-ebsa/our-activities/resource-center/fact-sheets/women-and-job-based-health.pdf>.

addition to highlighting the importance of SDM tools in palliative care, our learnings suggest that clinicians are key to SDM interventions and that cost information in SDM tools offer greater ability to make informed healthcare decisions. No longer an afterthought when making healthcare decisions, cost information that accompanies treatment options enhances SDM discussions.

FAIR Health will continue its work in this space. In April 2020 the Fan Fox and Leslie R. Samuels Foundation awarded FAIR Health a generous grant to create an SDM educational site for healthcare providers. This new, complementary initiative contemplates the development and dissemination of a provider-facing, online educational portal that will promote the use of the SDM tools to New York City-based providers serving older adults with serious illnesses. We will launch the new portal in March 2021.



## About FAIR Health

FAIR Health is a national, independent nonprofit organization dedicated to bringing transparency to healthcare costs and health insurance information through data products, consumer resources and health systems research support. FAIR Health qualifies as a public charity under section 501(c)(3) of the tax code. FAIR Health possesses the nation's largest collection of private healthcare claims data, which includes over 32 billion claim records and is growing at a rate of over 2 billion claim records a year. FAIR Health licenses its privately billed data and data products—including benchmark modules, data visualizations, custom analytics and market indices—to commercial insurers and self-insurers, employers, providers, hospitals and healthcare systems, government agencies, researchers and others. Certified by the Centers for Medicare & Medicaid Services (CMS) as a national Qualified Entity, FAIR Health also receives data representing the experience of all individuals enrolled in traditional Medicare Parts A, B and D; FAIR Health includes among the private claims data in its database, data on Medicare Advantage enrollees. FAIR Health can produce insightful analytic reports and data products based on combined Medicare and commercial claims data for government, providers, payors and other authorized users. FAIR Health's free, award-winning, national consumer websites are [fairhealthconsumer.org](https://fairhealthconsumer.org) and [fairhealthconsumidor.org](https://fairhealthconsumidor.org). For more information on FAIR Health, visit [fairhealth.org](https://fairhealth.org).

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