Developing a Shared Decision-Making Tool in Collaboration with Patients and Clinicians

Summary

Avalere used a human-centered design approach structured around patient preferences to help guide advanced breast cancer patients.

In 2017, Avalere and FasterCures released Version 1.0 of the Patient-Perspective Value Framework (PPVF) Initiative, a value assessment methodology that outlines a set of key considerations that are important to patients when making care decisions. Avalere built additional technical granularity into that model with the release last month of the PPVF scoring methodology. Avalere continues to work on different use cases for the PPVF, including how to support patients and clinicians at the point of care.

As part of this initiative, Avalere has developed an upstream shared decision-making (SDM) tool to help provide a roadmap for people in charting their care experiences. It has two primary aims:

1. To increase the consideration of patient preferences in clinical decision making
2. To help patients and families better understand and plan for their care experience
The prototype was initially created for patients with advanced breast cancer. Avalere plans to refine and test the tool in additional condition areas.

The tool is intended to be provided to a patient before treatment planning, to help inform the care visit. It is comprised of a set of questions and prompts organized in 4 key sections:

**Figure 1: Final Prototype Has 4 Key Components**

- **WHAT TO EXPECT**
  - “What To Expect as You Plan Your Care”
    - Intended to support advanced breast cancer patients understand the broad phases of their care experience and key decision points

- **PERSONAL GOALS**
  - “Clarifying Your Goals & Needs”
    - Intended to support the patient in thinking through their personal preferences (goals, expectations, needs) ahead of their treatment planning visit

- **CARE-RELATED PREFERENCES**
  - “Questions To Answer for Your Doctor”
    - Intended to support patients in sharing their care-related preferences with their care teams ahead of their treatment planning visit

- **CHECKLIST OF QUESTIONS**
  - “Questions To Ask Your Doctor & Care Team”
    - Intended to guide the patient-clinician conversation during the treatment planning visit, based on the patient and family’s preferences

The “Questions to Answer for Your Doctor” section of the prototype is a brief 7-question survey eliciting a patient’s decision-making style, spirituality, financial burden, and the top concerns that they would like to discuss during their upcoming treatment planning visit. This survey is the only piece of the tool that is intended to be shared with an oncologist ahead of the treatment planning visit, to provide them with key insights regarding the patient’s preferences that should be considered during the decision-making process. The development of the questions in this survey was led by Dr. Gabrielle Rocque, Assistant Professor, Hematology & Oncology, University of Alabama Birmingham School of Medicine, in collaboration with oncologists at the Duke
University School of Medicine and Intermountain Healthcare, as well as Avalere, Carevive and CancerCare. Avalere then tested these questions with advanced breast cancer patients. This section of the tool has not yet been published – as it is part of an ongoing study led by Dr. Rocque – however, it will be included in the version of the tool that will be piloted as part of Phase III of the PPVF Initiative.

**The Human-Centered Design Development Approach**

In a focus group convened by Cancer Support Community (CSC) and Avalere, patients shared their need for a “checklist” that outlines all the components of the PPVF in a way that can help guide their care decision-making and planning. Based on those insights, Avalere developed an initial prototype, and worked with CancerCare to identify 15 women with advanced breast cancer to participate in the development of the SDM tool. Avalere interviewed a diverse population, ranging from ages 42 to 79, and with varying levels of socioeconomic status (see here for further details on patient demographics).

During a 2-hour group interview, 7 women with stage IV breast cancer shared their experiences and provided feedback on the draft prototype of the tool. As part of an iterative co-development process, Avalere updated the tool based on the group feedback and brought updated versions back to another set of women with advanced breast cancer to collect their input in 1-on-1, in-depth interviews. In order to ensure incorporation of the clinician perspective, we also conducted interviews with social workers and oncologists to inform the development of the prototype.

**Avalere’s SDM Tool for Advanced Breast Cancer Patients**

Several themes emerged from the co-development process that highlight the decision-making and care planning needs of patients with advanced breast cancer:

1. **Patients and caregivers/family members want guidance in thinking through their care-related preferences**

Patients and caregivers/family members noted that they were overwhelmed at the time of diagnosis and felt that this tool included a range of considerations that they might have overlooked at that time. Patients expressed that our tool would have helped them structure their thinking and prioritize their thoughts before and during their visit, when they often expressed “going blank” and feeling overwhelmed by the limited time and volume of information to cover with their provider.
2. The amount of information that patients want upfront varies and can impact the patient-provider relationship

Our interviews suggest that patients have varying preferences on how much information they want to receive upfront about potential side effects and prognosis. How providers dose the information for their patients can impact the patient-clinician relationship. Patients in our interviews responded positively to the questions eliciting preferred decision-making style (see questions #1-3 on page 3 of the tool), which could provide guidance to clinicians on what information the patient is seeking at that time.

3. Patients are concerned about the direct and indirect costs of care

Most of the women interviewed expressed concerns over the costs of their care and, in many cases, financial stress impeded their access to care. Some women wondered how they would be able to pay for their medical bills and how their cancer care would impact their other finances (e.g., paying bills and making mortgage payments). Several women also worried about the indirect costs of care, including the costs of travel, childcare, and time spent away from work. Building on the work Avalere has conducted in collaboration with the Robert Wood Johnson Foundation, the tool includes two financial toxicity screening questions, and a host of questions that patients can ask their doctors to better explore the potential direct and indirect costs of their care (see pages 7 and 8).

What’s Next for the PPVF SDM Tool?

Avalere will pilot the SDM tool with provider partners to evaluate its impact when used as part of the care process. We are also developing the tool to serve the specific needs of multiple condition areas, building on the insights learned from co-development with patients who have advanced breast cancer.

To learn about partnership opportunities around the PPVF SDM tool, connect with us.