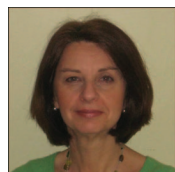


# Shared Decision Making: Promoting Best Practice

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With the welcomed increase in treatment options that we now have in the field of pulmonary hypertension (PH), it is important that our commitment to patients includes going beyond patient education and a presentation of benefits and risks to make sure we reach consensus on the choice of treatment. As health professionals we are increasingly encouraged to involve patients in their treatment decisions, recognizing them as experts with unique knowledge of their own preferences based on their values and willingness to comply.<sup>1</sup> In fact, noncompliance is less likely if both parties decide together which treatment is best and move forward with it. However, finding ways to elicit patients' preferences can be a considerable challenge. Physician bias or time constraints may influence how and to what degree these preferences are elicited, and many physicians wish to retain the imbalance of power between themselves and their patients, thus causing patients to be reluctant to share their preferences if they regard their doctor as more powerful.<sup>2</sup> Now that we have multiple treatment options, what are the best ways to promote shared decision making?

Since the president's commission first coined the term "shared decision making" over 30 years ago, the concept has become an ethical ideal.<sup>3</sup> This concept goes beyond simply informing the patient of the risks and benefits of therapy options and then making recommendations, but rather goes further by assisting the patient in becoming dynamically involved in the

decision process and, ultimately, the outcome.<sup>4</sup> One common example of such a treatment decision would be whether the patient should initiate intravenous or subcutaneous prostacyclin for functional class III pulmonary arterial hypertension (PAH). How do we facilitate a final decision that would satisfy both the clinicians and patient? What would happen if the patient prefers to start with the nebulized form of prostacyclin despite progressive symptoms rather than an intravenous formulation recommended by the physician and/or team? These can be daunting decisions encountered repeatedly in practice. In such situations, the stresses of the patient's clinical status as well as information overload may influence the ability of that patient to take an active role in choosing the best long-term therapy option. Compliance may also become an issue if he/she did not take an active role in the treatment decision. Another scenario would be a conflict between what the patient wants and what a family member expects. A clue to this issue, termed "decisional dilemma," may be when the patient asks caregivers, "what would you do?" This dilemma can be even more concerning while obtaining informed consent for participation in a clinical drug trial.

How a physician makes a decision and how a patient and his/her family decide on a treatment can be accomplished through different approaches.<sup>5</sup> Clinicians rely on utility theory or statistics to analyze best outcomes. The best example of this is the current evidence-based treatment algorithms derived from 15 years of clinical trials.<sup>6</sup> These are also based on a consensus within the PH medical community and identified as core principles within our practice. On the other hand, patients and family members are more likely to use the information-processing theory, focusing on cognitive and affective variables integrating their values and preferences. One way in which we as team members can bridge this gap of utility theory vs informa-

tion processing is by using a patient decision aid. Decision aids or tools help the patient become an informed participant and assist in reaching decisions in line with the patient's values, preferences, and life goals while taking into consideration the information provided by the physician.<sup>7</sup> Over the last decade empirical research examining the importance of "shared decision making" has fueled increased interest in shifting it from ethical ideal to actual practice by a growing movement of developing and standardizing decision aids.<sup>8</sup>

The Ottawa Personal Decision Guide (OPDG), devised by O'Connor, Stacey, and Jacobson at the Ottawa Hospital Research Institute, is useful in assisting the decision-making process for patients with PH who are deciding on options for life-long therapies. The OPDG (Figure 1) helps the patient delineate options and asks him/her to place personal weights on benefits and risks. In addition, the OPDG further assists the patient in clarifying personal values and support systems. This tool should be used as a complement, rather than a replacement, for counseling and discussions with the medical team. It can be an excellent option for patients who need assistance identifying the best treatment option. Since it is interactive and available in 4 languages, it is easy to use and applicable to a varied group. The patient can use this tool to focus on *knowledge* (needed facts and possible questions), *values* (what matters most), and *supports* (financial, opinions, pressures). Once completed, it can then be printed and brought to the clinic as a catalyst for an open discussion with the PH team.

Information alone, however, is not always sufficient for patients in making such an important decision. Providing information to the patient should only be a prerequisite for assistance in making the best choice for lifelong treatment. All parties must contribute to the treatment decision for the process to be shared. The use of a decisional aid such as the OPDG is just one way in which we can facilitate information and preference sharing lead-

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**Ottawa Personal Decision Guide** Date: \_\_\_\_\_

**Decision:** What decision do you face? \_\_\_\_\_  
 When do you need to make a choice? \_\_\_\_\_  
 How far along are you with making a choice?  
☐ not thought about options ☐ thinking about options ☐ close to making a choice ☐ already made a choice  
 Are you leaning toward one option? ☐ No ☐ Yes, which one? \_\_\_\_\_

**Certainty:** Do you feel sure about the best choice for you? ☐ No ☐ Yes

**Knowledge:** Do you know which options are available to you? ☐ No ☐ Yes  
 Do you know both the benefits and risks of each option? ☐ No ☐ Yes

**Values:** Are you clear about which benefits and risks matter most to you? ☐ No ☐ Yes

A. In the balance scale below, list the options and main benefits and risks that you already know.  
 B. Underline the benefits and risks that you think are most likely to happen.  
 C. Use stars [★] to show how much each benefit / risk matters to you: 5 stars means it matters 'a lot'; No star means 'not at all.'

	Benefits (reasons to choose this option)	How much it matters (★)	Risks (reasons to avoid this option)	How much it matters (★)
Option 1				
Option 2				
Option 3				

**Support:** What role do you prefer in making your choice?  
☐ I prefer to share the decision with \_\_\_\_\_  
☐ I prefer to decide myself after hearing the views of \_\_\_\_\_  
☐ I prefer that someone else decides. Who? \_\_\_\_\_

Do you have enough support and advice from others to make a choice? ☐ No ☐ Yes  
 Are you choosing without pressure from others? ☐ No ☐ Yes

Who else is involved? (name)	Which option does this person prefer?	Is this person pressuring you?	How can this person support you?
	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes

**Next Steps:** This section suggests some next steps based on your needs. Check any items you would like to try.

**Knowledge (If you feel you do not have enough facts):**  
☐ List your questions.  
☐ Note where to find answers. (e.g. library, health professionals, counsellors)  
☐ Find out about the chances of benefits and risks.

**Values (If you are not sure what matters most to you):**  
☐ Review stars in the balance scale to see what matters to you.  
☐ Find people who know what it's like to experience the benefits and risks.  
☐ Talk to others who have made the decision.  
☐ Read stories of what mattered most to others.  
☐ Discuss with others what matters most to you.

**Support (If you feel you do not have enough support):**  
☐ Discuss your options with a trusted person. (e.g. health professional, counsellor, family, friends)  
☐ Find out what help is on hand to support your choice. (e.g. funds, transport, child care)

**(If you feel pressure from others):**  
☐ Focus on opinions of others who matter most.  
☐ Share your guide with others.  
☐ Ask others to complete this guide. Find areas of agreement. When facts disagree, agree to get more information. When you disagree on what matters most, respect the other's opinion. Take turns to listen and then mirror back what the other has said that matters most to them.  
☐ Find a neutral person to help you and others involved.

**Other plans**  
☐ Describe \_\_\_\_\_

Version February 2007 © O'Connor, Stacey, Jacobsen 2004.

**Figure 1: Ottawa Patient Decision Tool. Reprinted with permission from the Ottawa Hospital Research Institute Clinical Epidemiology Program Patient Decision Aid Research Group.**

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ing to a focused discussion. The imaginative use of available decision aids together with our evidence-based treatment algorithms and risk assessments generated from clinical trials and registries keep us in the mainstream of health care. We must realize that shared decision making is not an illusion but rather another way that we can work collaboratively with our patients to achieve the best outcomes. As members of the PH Resource Network, we must work together with our physician colleagues to find timely and cost-effective ways to meet this challenge.

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