

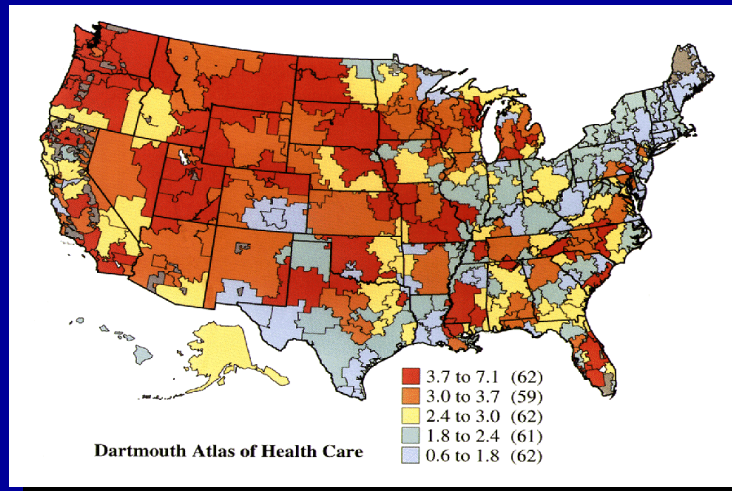
# **HELPING PATIENTS MAKE HEALTH CARE DECISIONS**

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**Helping Patients Make Health Care Decisions**

## Practice Variation: Is Geography Destiny?



In other lectures in this series, we have talked about the possible causes and consequences of geographic variations in the provision of health care.

And we have raised questions about the extent to which those practice variations may be warranted or unwarranted.

## Practice Variation: Warranted Sources

### Accurate information + ...

- ✓ Variation in attitudes towards risk
- ✓ Variation in attitudes towards time tradeoffs
- ✓ Variation in preferences for different kinds of treatments
- ✓ Variation in preferences for different health outcomes
- ✓ Variation in preferences for participation in decision making

We could argue that there are circumstances when an observed practice variation is warranted (that is, understandable and appropriate).

Given an accurate and clearly understood background of information about what is at stake in a health care decision, the patients in different geographic regions may genuinely differ in their attitudes towards key aspects of that decision.

For example, there may be geographic variations in the distributions of attitudes towards the risk levels and time commitments involved in different treatment options.

There may be variations in preferences for the actual protocols involved in different kinds of treatments,

in preferences for the different health outcomes that can occur with different treatments,

and in preferences for participating in health care decision making in the first place.

## **Practice Variation: Unwarranted Sources**

### **Practices vary because ...**

**Gaps in research**

**Inadequate transfer of knowledge**

**Practice not evidence-based**

**Institutional / systems barriers**

**Barriers due to social roles**

**Inadequate patient education**

**Inattention to individual preferences**

On the other hand, we could argue that there are circumstances when an observed practice variation is unwarranted, in that it is based on questionable forces.

For example, practice variations would be understandable but questionable if they are due to the kind of shaky evidence base that arises when the clinical research background is incomplete or inaccurate.

Even if the evidence is clear and compelling, there could be problems with the transfer of that knowledge to practitioners, or there may be motivational, organizational, or social resistance to the principles of evidence-based practice. These barriers would in turn translate into unwarranted variations in practice.

Even if the evidence is clear and compelling, and there is a commitment to evidence-based practice, there could be difficulties in ensuring that patients have enough awareness of what's at stake to be able to provide informed consent to treatment. To the extent that subsequent variations were not based on informed choice, they could also be considered unwarranted.

Furthermore, even if the evidence is clear and compelling, practice is evidence-based, and patients have enough information, health care providers may pay inadequate attention to individual differences in preferences regarding decision making roles, risk, time, treatment processes, and health outcomes.

**Could ...**

**“Shared  
Decision  
Making”  
&  
“patients’  
decision  
aids”**



**maintain warranted  
&  
resolve unwarranted  
variation ?**

Given this background argument, these 2 lectures are based on the working hypothesis that the principles of “Shared Decision Making” and the use of “patients’ decision aids” in clinical practice may be one way to reduce the sources of unwarranted practice variation, while supporting warranted variations.

## First, some background ...

- Decisional conflict
- The concept of decision support

See:

Annette O'Connor, Ph.D., U. of Ottawa

[www.ohri.ca/programs/clinical\\_epidemiology/  
OHDEC/practice](http://www.ohri.ca/programs/clinical_epidemiology/OHDEC/practice)

However, before talking about Shared Decision Making and patients' decision aids in detail, which I will do in the next lecture, it would be useful to look at 2 sets of core ideas.

The first set involves what's going on when people are having difficulty making decisions about their health care. This kind of difficulty is referred to as "decisional conflict".

The second set of ideas refers to the ways that health care professionals can use their clinical skills to help patients who are in decisional conflict, by providing "decision support".

These ideas are being tested by decision scientists – particularly by Dr. Annette O'Connor in the Clinical Epidemiology Department of the University of Ottawa, Canada, whose website address appears here.

## **DECISIONAL CONFLICT: WHAT IS IT?**

- **ACCEPT ?    REJECT ?**
- **Janis & Mann, Decision Making, 1977**

So what is “decisional conflict”?

According to the psychology literature, it is experienced by an individual who simultaneously tends to both accept and reject a given course of action.

## WHEN DOES IT OCCUR?

- Choices with:
  - Risky, uncertain outcomes
  - Need to make value judgments
  - Anticipated regret

Decisional conflict occurs in decision situations that can be characterized in 3 ways....

They are chancy – that is, alternative options can lead to risky, uncertain outcomes;

They oblige the decision maker to make value judgments about the losses versus the gains associated with options; and

They generate anticipated regret over

rejecting options that have positive aspects &

accepting options that may lead to negative consequences.

## MANIFESTATIONS OF DECISIONAL CONFLICT

- Uncertain
- Concerned
- Wavering
- Delaying
- Questioning
- Preoccupied
- Tense / distressed / panicked

What would the clinician observe in a patient who was experiencing decisional conflict?

The patient may talk quite a bit about his or her uncertainty about the choice, and his or her concern about the outcomes of that choice.

He or she would waver between the alternative options, and may delay making the decision for a considerable length of time.

The patient may engage in difficult questioning about his or her own values, and be preoccupied with the decision

Furthermore, the patient may demonstrate the signs and symptoms of distress, ranging from tension to outright panic.

This kind of decisional conflict can, of course, be generated by ...

Situational decisions, like those involving career and living arrangements;

Maturational decisions, like birth control or retirement; and

Lifestyle changes, like exercise programs or smoking cessation.

Here, we are particularly concerned with the kind of decisional conflict that can be stimulated by

Treatment Related decisions, involving Screening / Diagnosis / or Medical-Surgical choices.

## TREATMENT-RELATED DECISIONAL CONFLICT:

Is the Rx ...

- An Option ?
- A Guideline ?
- A Standard of Care ?



increasing uncertainty  
&  
increasing likelihood  
of decisional conflict

An important issue to bear in mind is that the likelihood of treatment-related decisional conflict is partially due to whether the treatment under consideration is a

Standard of Care

a Guideline

or an Option.

With “STANDARDS OF CARE”, there is strong evidence for the effectiveness of the treatment, and strong agreement among patients that these are valued interventions. A couple of examples are insulin for Type I diabetes, and antibiotics for bacterial infection.

With “GUIDELINES”, there is strong evidence regarding effectiveness, but less agreement among patients about the value of the possible outcomes, in that not all agree that the benefits outweigh the potential risks or harms involved. Amniocentesis for pregnant women over the age of 35 is an example.

With “OPTIONS”, both the evidence about the effectiveness in terms of achieving or avoiding particular outcomes is unclear, and the agreement on values is highly variable. Tamoxifen for healthy women at high risk for breast cancer is an example of this kind of situation.

SO different treatment decision situations tend to fall at different points on this “uncertainty continuum”. Those situations in which there is inherently more uncertainty are more likely to generate decisional conflict in patients.

## SOURCES OF Rx-RELATED DECISIONAL CONFLICT

- Situation inherently difficult
  - Potential advantages weighed against...
  - Potential disadvantages
- +
- Modifiable factors can make a difficult decision even more difficult

OK – So Treatment-Related Decisional Conflict can arise just from the inherent, unalterable difficulties in the situation itself.

It's important to note that often there also are modifiable factors that can make a difficult decision even more difficult.

## WHAT CAN MAKE IT WORSE?

- Lack of knowledge
- Unrealistic expectations
- Unclear values
- Unclear perceptions of others
- Social pressure
- Lack of support
- Lack of DM skills / self-confidence
- Lack of resources to implement

These modifiable factors include the following.

The patient may ...

lack knowledge or hold unrealistic expectations about what is involved in treatment and what the outcomes might be;

may be unclear about his or her own attitudes towards the desirability or undesirability of these processes and outcomes;

may be unclear or have formed inaccurate assumptions about what others usually decide under the same circumstances;

may be experiencing a lack of support or undue social pressure to decide one way or the other;

may feel that he or she doesn't have the self-confidence or skills to engage with this decision;

or may lack the resources needed to put particular action plans into place.

## **BECAUSE THESE ARE MODIFIABLE FACTORS ...**

- Idea of “decision support” as a clinical skill
- Clinical course re. teaching this skill
- Here, we hit the top notes:
  - Assessing decision needs
  - Providing decision support
  - Evaluating decision support
- Based on Ottawa Framework

Now – because these are modifiable factors, we can think in terms of “decision support” as a teachable clinical skill.

There are entire clinical courses designed to teach this skill – see, for example, the University of Ottawa website referred to earlier.

In this and the next lecture, there is time to only hit the top notes regarding:

Assessing individual decision needs

Providing individualized decision support

Evaluating the effectiveness of decision support

## **ASSESSING DECISION NEEDS**

- 1. Perceptions of decision itself**
- 2. Perceptions of others involved**
- 3. Perceptions of available resources**

**Are any of these “sub-optimal”?**

So the first clinical step in helping a person who is experiencing treatment-related decisional conflict is to carry out a systematic assessment of his or her perceptions of the decision situation, of the other people involved in the decision, and of the resources available to deal with the decision and its consequences. This assessment would involve gauging whether any of these elements are “sub-optimal”, as outlined in the next few slides.

## 1. “SUB-OPTIMAL” PERCEPTIONS OF DECISION ITSELF

- Lack of Readiness to Make Decision
- Inadequate Knowledge
- Unrealistic Expectations
- Unclear Values

“Sub-optimal” perceptions of the decision itself involve a number of issues.

For example, there could be mismatches between when a person believes a decision has to be made and whether or not he or she feels ready to do this.

On the other hand, the person may be ready to engage in deliberation about the problem, but does not have enough clearly-understood information about the basic disease process and the treatment options to do this meaningfully.

Or the person might have unrealistic expectations – that is, distortions in understanding the likelihood of encountering risks or gaining benefits.

Or the person might be knowledgeable and realistic in an objective sense, but be quite unclear about how he or she really feels about the personal values at stake in the decision situation.

## 2. “SUB-OPTIMAL” PERCEPTIONS OF OTHERS INVOLVED

- Unclear re. others’ opinions & practices
- Unwanted social pressure
- Inadequate support support
- Mismatch between actual & preferred roles in DM

“Sub-optimal” perceptions of the others involved in the decision also refers to a range of issues.

For example, the person may want to know – and not have access to – information about what other patients and providers in a similar situation have done, about their reasons, and about actual variations in choices.

He or she may be feeling under unwanted pressure from others like the clinician or family members to select one option over the other. Or the person might feel as if the social support he or she needs to engage with this decision is missing.

The person might also feel as if he or she would like to be more or less actively engaged with the actual decision, but that others are holding different assumptions about his or her preferences for participating in decision making in the first place.

### **3. “SUB-OPTIMAL” PERCEPTIONS OF AVAILABLE RESOURCES**

- **Limited self-confidence**
- **Limited skills in communication**
- **Limited skills in deliberating about options**
- **Limited material support (finances;  
accessible programs for following through)**

Finally, the individual may have problems with getting together the resources he or she needs to grapple with the decision.

For example, there may be low levels of confidence about in one's ability to make decisions,

limited skills in communication,

limited skills in deliberating about options,

and limited material support to actually draw upon after the decision has been made.

## **PROVIDING DECISION SUPPORT**

- **Tailored to assessment of individual**
- **Therefore, particular emphasis re. ...**
  - **Provide information (Eg. re. IHD & Rx) ?**
  - **Realign expectations re. risks / benefits ?**
  - **Clarify values re. acceptable / unacceptable ?**
  - **Improve “decision competency” skills ?**
  - **All of the above ?**

Then, based on this individualized assessment, the clinician would provide the particular kind of decision support that could most help the individual.

Therefore, some individuals decision support might involve a particular emphasis on the provision of information.

For others, the emphasis might be on helping them gain more realistic expectations about the risks and benefits involved in the situation.

Others might have adequate and accurately understood information, as well as quite realistic expectations, but need considerable help with clarifying for themselves what really is acceptable or unacceptable in the choice situation.

Still others may be fine in terms of information, expectations, and values, but may need help with weighing this all out and communicating their overall preferences to their clinician.

## **At the same time ...**

- **Gender-sensitive**
- **Appropriate to age, developmental stage, education, ethnic / cultural background**
- **Flexible re. preference for participation in DM in first place**
- **Flexible re. physical, cognitive, emotional effects of illness on DM abilities**

It is important to note that, at the same time, this individualized decision support ideally would be provided in a way that is gender-sensitive,

appropriate to the patient's age, developmental stage, education, ethnic / cultural background,

flexible with regard to the patient's preference for participation in DM in first place,

and sensitive to the physical, cognitive, and emotional effects of illness on DM abilities.

## PROVIDING DECISION SUPPORT

- Clinicians can systematically provide decision support without formal decision aids (DAs)
- However, sometimes DAs can be very helpful with this process
- Caution:  
Simply giving a patient a DA does not = “decision support” or “shared decision making”

In summary, it's also important to note that clinicians can effectively provide this kind of systematic decision support without formal decision aids (DAs).

However, sometimes DAs can be very helpful with this process. In the next lecture, I will talk more about the role of DAs in decision support.

But the crucial cautionary point to carry into the next lecture is that simply giving a patient a DA does not = “decision support” or “shared decision making”.

Let's talk next about what we mean about Shared Decision Making and patients' decision aids....