Slide 1: Eliciting Patients' Values and Preferences in Decision Making

Hilary Llewellyn-Thomas, PhD
Emeritus Professor
Dartmouth Medical School, Hanover, NH, USA

R. Trafford Crump, PhD
Post-Doctoral Research Fellow
Centre for Health Services and Policy Research
University of British Columbia, Vancouver, BC, Canada

Slide 2: INTRODUCTION

- The communication challenges in values /preferences elicitation (V/P elicitation) are not unique to clinician-patient interaction.
    - health policy; health economics; practice guidelines;
    - human judgment and decision making;
    - market research; etc.
- Considerable debate across these disciplines re. V/P elicitation.

Slide 3: INTRODUCTION (cont'd)

- We've tried to be agnostic in our approach.
- We do not argue for a particular disciplinary perspective.
- We highlight a range of…
    - assumptions
    - methodological approaches
    - research issues

Slide 4: INTRODUCTION (cont'd)

- V/P elicitation with patients who could benefit from…
  "decision support"
  as they consider a…
  "preference-sensitive health care decision".
- How we are using these terms?

Slide 5: INTRODUCTION (cont'd)

- Preference-Sensitive Health Care Decision =
    - 2 or more appropriate therapeutic options.
    - No consensus that benefits of 1 option outweigh possible risks of the other option(s).
    - Selection of option depends on individual patient's informed preferential attitudes…

a) towards positive and negative attributes of each option, as well as…

Source: Eisenberg Center Conference Series 2011, Differing Levels of Clinical Evidence: Exploring Communication Challenges in Shared Decisionmaking, Effective Health Care Program Web site (http://www.effectivehealthcare.ahrq.gov/index.cfm)

b) towards scientific uncertainty when evidence is thin or of poor quality.

Slide 6: INTRODUCTION (cont'd)

- Decision Support =
    - Helping arrive at informed, preference-based choice among options.
    - Can be provided by patient's clinician or a decision "coach".
    - In one-on-one or group sessions; face-to-face or using communication technology (e.g., telephone, internet).
- range of frameworks.
- We base our comments on the Ottawa Decision Support Framework.

Slide 7: INTRODUCTION (cont'd)

- Ottawa Decision Support Framework =
    - Step 1: Realizing there's choice to be made
    - Step 2: Comprehending information
    - Step 3: Clarifying ("eliciting") values and preferences
    - Step 4: Identifying social and material resources
    - Step 5: Forming an action plan
- Iterative — not lock-step/linear.
- At each step, particular deliberative goals and communication issues.

Slide 8: INTRODUCTION (cont'd)

- "Value" = detailed subjective evaluation of desirability/undesirability of each option's specific attributes:
    - its protocol; its possible benefits; its potential harms.
- Therefore, "eliciting values" = clinician/decision coach + patient gain mutual insight into patient's attitudes towards…
    - each option's positive and negative attributes,
    - attribute tradeoffs she is/isn't willing to make.

Slide 9: INTRODUCTION (cont'd)

- "Preference" = holistic subjective evaluation of overall desirability/undesirability of each option relative to alternatives.
- Therefore, "eliciting preferences" = clinician/decision coach + patient work together to identify overall favored option.

Slide 10: OUTLINE

- A. Five "meta-communication" challenges in V/P elicitation.
- B. Implicit/explicit approaches→Focus on explicit approaches to V/P elicitation.
- C. Key research problems in V/P elicitation.

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- D. Process and outcome criteria for "good" V/P elicitation.
- E. Conclusion.

Slide 11: "META-COMMUNICATION" CHALLENGES

- Ideally, V/P elicitation for patients who:
    - Have not already formed a strong prior informed preference;
    - Wish to participate in decision making;
    - Uncertain about attitudes towards options and attributes;
    - Believe assistance sorting out attitudes will be helpful.
- Not imposed if pt. does not wish to participate, or if sorting out unclear attitudes would be distressing.
- Challenge 1 Assess pt.'s readiness to participate.

Slide 12: "META-COMMUNICATION" CHALLENGES (Cont'd)

- Ideally, motivated by genuine, ethically-justifiable interest in fostering safe, patient-centered care, by helping pt. to:
    - Understand and weigh personally important attributes;
    - Communicate those attitudes to clinician/coach;
    - Select option consistent with those attitudes;
    - Negotiate system so informed, preference-based choice is acknowledged and acted upon
- Challenge 2 Pt. and clinician/coach agree on goals of V/P elicitation.

Slide 13: "META-COMMUNICATION" CHALLENGES (Cont'd)

- Ideally, avoids imposing onto pt. assumptions about what are most relevant attributes of options under consideration.
- Challenge 3 Clinician/coach/designer of patients' decision aid (PtDA) ensures opportunities for pt. to ad individually-relevant attributes to pre-identified roster of attributes.

Slide 14: "META-COMMUNICATION" CHALLENGES (Cont'd)

- Ideally, free of framing and sequencing effects that could covertly influence pt. to favor or dismiss particular options.
- Challenge 4 Clinician/coach/PtDA designer informs pt. that artefacts could leak into V/P elicitation + provides opportunities to offset effects if they should occur.

Slide 15: "META-COMMUNICATION" CHALLENGES (Cont'd)

- Ideally, leaves room for iteration.
    - Formulation and reporting of values + selection of favored option are dynamic, unfolding phenomena.

Source: Eisenberg Center Conference Series 2011, Differing Levels of Clinical Evidence: Exploring Communication Challenges in Shared Decisionmaking, Effective Health Care Program Web site (http://www.effectivehealthcare.ahrq.gov/index.cfm)

    - Some individuals' attitudes about attributes + favored option remain constant; others report shifts with insight and experience.
- Challenge 5 Foster mutual awareness of emergent nature of values/preferences. Provide opportunities to review, reconsider, revise.

Slide 16: B. SOME APPROACHES TO V/P ELICITATION

- Implicit Approaches
- Explicit Approaches

Slide 17: IMPLICIT APPROACHES

- General procedure = linear, pre-determined, script-like coaching or patients' decision aid (PtDA):
    - First provides clinical information re. decision.
    - Then encourages pt. to consider personal attitudes before choosing.

Slide 18: IMPLICIT APPROACHES: Several Ways to Encourage Pt to Consider Personal Attitudes

One involves…

- Describing physical, social, emotional effects of experiencing each option's benefits and harm.
- Assumption Vivid descriptions help pt. sort out values and identify favored option.

Slide 19: Some other implicit ways involve…

- Illustrating how different groups of pts. value options' attributes differently, and therefore make different choices.
- Presenting recorded interviews with pts. ("testimonials")…
    - re. their attitudes towards options' attributes, and
    - re. how they based their choices on those attitudes.

Slide 20: Assumptions underlying these other implicit ways…

- Illustrative examples/testimonials help pt. to appreciate importance of her own values.
- Identifying with illustrative examples/testimonials most closely matching herself, pt. better able to clarify own attitudes and then make choice.

Slide 21: WHY "IMPLICIT"?

- General assumption = pt. implicitly will:
    - understand importance of own subjective attitudes,
    - weigh out relative desirability of options and their attributes, then
    - derive overall preference for one option compared to the others.

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- Is this "good enough"? What if…
    - Options/attributes are complex and multi-faceted?
    - Wish to reveal deep processes whereby V/P are constructed, communicated, and acted on?

Slide 22: EXPLICIT APPROACHES

- General procedure = coach/PtDA:
    - First provides clinical information re. decision.
    - Then engages pt. in hands-on exercises that deliberately work with processes whereby attribute-values…
        - are formulated and traded-off, and
        - are integrated into selection of preferred option.

Slide 23: Assumptions underlying explicit approaches…

- Deeper insight into values than by passive viewing of linear-formatted PtDA or listening to clinician/coach's script.
- Reveal and communicate to family and clinician/decision coach the underlying rationale for pt.'s unique set of values /preferences
- May, in turn, help ensure pt. actually receives preferred option.

Slide 24: EXPLICIT APPROACHES: Indirect

Involve…

- Presenting pt. with pre-designed set of evaluative tasks.
- Applying a computational strategy to full set of responses to those tasks.
- End result is indication of pt.'s overall favored option, at either the "coarse-grained" or "fine-grained" level.

Slide 25: EXPLICIT APPROACHES: Some Indirect (cont'd)

Coarse-Grained:

- Decision Analysis

Fine-Grained:

- Conjoint Analysis
- Analytic Hierarchy Process

Slide 26: EXPLICIT APPROACHES: Direct

- Do not use a computational strategy.
- Work directly with pt.'s "fast and frugal heuristics" in real time.

Source: Eisenberg Center Conference Series 2011, Differing Levels of Clinical Evidence: Exploring Communication Challenges in Shared Decisionmaking, Effective Health Care Program Web site (http://www.effectivehealthcare.ahrq.gov/index.cfm)

- End result is also an indication of pt.'s overall favored option, at either the "coarse-grained" or "fine-grained level.

Slide 27: EXPLICIT APPROACHES: Some Direct (cont'd)

Coarse-Grained:

- Card-Sorting
- Leaning Scale

Fine-Grained:

- Balance Technique
- Dynamic Tailoring

Slide 28: C. SOME RESEARCH PROBLEMS IN V/P ELICITATION

RELEVANT TO:

- Education researchers
    - Teach clinicians/coaches re. communication skills for V/P elicitation
- Designers of formal PtDAs
    - Help patients reveal their individual informed V/Ps.
    - Help scientists to study how pts. formulate, describe, discuss, and act upon V/Ps.

Slide 29: V/P Elicitation as Clinical Skill: Research Issues in Clinical Education

- Broader Perspective — In the Full Patient-Clinician/Decision Coach Transaction
- Narrower Perspective — In the V/P Elicitation Phase of Patients' Decision Support

Slide 30: In the Full Patient-Clinician/Decision Coach Transaction

TO TEACH DECISION SUPPORT AS CLINICAL SKILL…

- Which communication theories best guide such teaching?
- What curricular models for integrating into clinical education?
- What teaching materials for different clinical professions /disciplines?
- Which evaluative approaches for assessing successful teaching?
- What strategies to embed continuing education in different practice settings?
- What kinds of organizational programs to maintain/update successful training effects?

Slide 31: In the V/P Elicitation Phase of Decision Support

TO TEACH V/P ELICITATION AS A CLINICAL SKILL…

- Which communication theories best guide such teaching?
- What are best strategies for teaching clinicians…

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- *Assess* V/P uncertainty
- *Plan* appropriate individualized approach to V/P elicitation
- *Implement* that individualized V/P elicitation plan
- *Evaluate* effectiveness of that individualized V/P elicitation plan

- Must theories/strategies be modified for different clinical professions/ disciplines?

Slide 32: V/P Elicitation as Scientific Field: Research Issues in the Design of PtDAs

- Implicit Approaches — Testing Assumptions
- Explicit Approaches — Complex Questions

Slide 33: Implicit Approaches – Testing Assumptions

- Little known about whether vivid stories inadvertently influence pts' choices.
  and…
- Attempts to present fully "balanced" set of pts' stories may affect choices in invalid ways:
  - Even a couple of options with only a few attributes could overwhelm the patient.
  - Could introduce order and sequencing effects, biasing her choice.
  - May over-represent relatively rare negative outcomes or under-represent common positive outcomes.

Slide 34: Explicit Approaches – Complex Questions

- Sub-groups with "meta-preferences"? Effects of matching/mis-matching?
- Effects of different PtDA media (e.g., paper-based vs. electronically-based Card Sort)?
- Results of a direct approach consistent with the results implied by an indirect approach? When does consistency or inconsistency matter?
- Different direct approaches "better" at clarification re. uncertainty?
- Results of 2 different direct strategies consistent with each other? Under what conditions does that matter?
- How simple or complex does a direct V/P elicitation exercise "need" to be?

Slide 35: Explicit Approaches – Complex Questions (cont'd)

- Can pts' paths through dynamically-tailored V/P elicitation exercises be tracked, as they sort out their attitudes?
- Are particular pathway patterns associated with different…
  - pt. socio-demographic or clinical characteristics?
  - levels of baseline decisional conflict?
  - outcome levels of information comprehension or anxiety?
  - "downstream" effects on actual choices and the outcomes of care?

Slide 36: Explicit Approaches — Complex Questions (cont'd)

Source: Eisenberg Center Conference Series 2011, Differing Levels of Clinical Evidence: Exploring Communication Challenges in Shared Decisionmaking, Effective Health Care Program Web site (http://www.effectivehealthcare.ahrq.gov/index.cfm)

- How stable/labile are results using coarse-grained and fine-grained explicit approaches to V/P elicitation?
- Is subsequent actual choice behavior consistent with preferences implied by earlier V/P elicitation?
- When do inconsistencies imply that V/P elicitation has messed things up for the patient?
- When are inconsistencies the natural and valid result of deeper consideration of the decision problem?

Slide 37: KEY METHODOLOGICAL ISSUE:

- Are classic measurement concerns of primary importance here?
- Or are other process/outcome criteria of greater importance when investigating dynamic phenomena of V/P elicitation in comparative study designs?
- Do we, in effect, need an organized taxonomy of comparative criteria for "good" V/P elicitation approaches?

Slide 38: SOME PROCESS COMPARATIVE CRITERIA:

- Operational criteria
- Cognitive psychology criteria

Slide 39: SOME OUTCOME COMPARATIVE CRITERIA:

- Construct validity criteria
- Clinical criteria
- Ethical criteria
- Decision criteria

Slide 40: SO FAR:

- Methodological work about comparative criteria has primarily unfolded in the larger arena of decision support/shared decision making…
- …rather than in the narrower field of developing comparative criteria for V/P elicitation approaches per se.

Slide 41: HOWEVER:

- Some work is underway addressing the problem of V/P-elicitation-focused comparative criteria:
    - Researchers @ University of Michigan using human factors engineering principles to develop set of criteria for evaluating usability of specific V/P elicitation techniques.[1]
    - Crump and Wedley drawing from cognition and decision modeling to develop framework for assessing processes in V/P elicitation.[2]

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Slide 42: CONCLUSION

- Highlighted role of V/P elicitation in pts' decision support.
- Outlined implicit and explicit approaches and their assumptions.
- Raised research issues inherent in these different approaches.
- Suggested process and outcome criteria re. "goodness" of different approaches to V/P elicitation.

Slide 43: CONCLUSION (2)

Also …

- Highlighted "nested" nature of the theoretical and methodological issues in V/P elicitation.
- Interdisciplinary strategies are required to address those nested issues.

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