Ottawa Decision Support Framework:
Update, Gaps and Research Priorities
May 6-7, 2010

Since 1995, the Ottawa Decision Support Framework (ODSF) has been used to assess patients' decisional needs, design interventions (e.g. patient decision aids; coaching), measure changes in patient outcomes (e.g. decisional conflict scale) and train healthcare professionals. The objectives of this workshop were to:

a) Review the synthesized evidence on the ODSF and related knowledge translation tools, instruments, and implementation interventions;
b Identify gaps in the evidence-base; and
c) Establish research priorities to address the identified gaps and thereby advance the scientific evidence to support patient involvement in decision making.

This report summarizes the synthesis of evidence and research priorities for: a) the framework; b) decisional needs; c) the decisional conflict scale; d) patient decision aids; and e) decision coaching and training.

The Ottawa Decision Support Framework

The Ottawa Decision Support Framework explains the relationship between participants' decisional needs, decision quality, and decision support.

Decision quality is defined as: a) informed (the patient understands key facts about their condition and their options and has realistic expectations of the probabilities of benefits and harms); and b) consistent with personal values (the chosen option is consistent with the outcomes that matter most to the informed patient).

The quality of decisions is determined in part by the extent to which a participants' decisional needs are addressed. Decisional needs include personal uncertainty about the best course of action and related modifiable factors such as inadequate knowledge, unrealistic expectations, unclear values, inadequate support or resources; complex decision type; urgent timing; unreceptive stage of decision making; polarized leaning toward an option; and participants' characteristics such as cognitive limitations, poverty, limited education, or physical incapacitation.

Decision support, which is tailored to needs, can improve decision quality by providing clinical consultation, decision aids, and coaching. Decision support includes: clarifying the decision and the patient's needs; providing facts and probabilities; clarifying values; guiding deliberation and communication; and monitoring/facilitating progress in decision making.

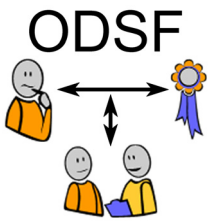
In the workshop the priorities for research on the framework were to:

- explore how the framework is applicable to a cascade of decisions over time, and to current changes in social networking and web 2.0
- update the theories underlying the framework
- determine the validity of the framework when used in an upstream intervention to develop capacity in health decision making with teens and young adults in high schools and post secondary institutions

Decisional Needs of Participants

Decisional needs have been examined in three large population surveys, 10 smaller needs assessments, 34 baseline measures of need in interventions studies, and 28 usual care measures of need in randomized controlled trials of decision aids. Findings revealed that about 55% of patients facing decisions experience decisional conflict (personal uncertainty). Consistently across studies decisional needs are evidenced by unrealistic expectations, low knowledge scores, and feeling uncertain, uninformed, unclear about values for outcomes, and unsupported. Many patients' needs are not resolved with usual care,

indicating the need for more targeted interventions. As well, decision characteristics and personal/clinical characteristics influence the frequency of need.



Research priorities identified at the workshop were to:

- implement measurement of decisional needs in routine clinical care
- assess needs for chronic care decisions with multiple options and attributes
- explore needs in more diverse populations (e.g. cultures, socio-economic status, health literacy)

Decisional Conflict Scale

The Decisional Conflict Scale (DCS) is a 16-item instrument measuring personal uncertainty about the decision and the factors contributing to uncertainty. The instrument is valid, reliable (Cronbach's alpha 0.78-0.89; test-retest >0.80), responsive to change (effect size 0.4 to 0.8), and reliable in a nested study design (e.g. patients nested under providers nested under clinics). Few items were found to be unhelpful in distinguishing between high and low decisional conflict thus suggesting that a simpler version may be possible. Other formats include: a simpler 10-item version, the 4-item SURE designed as a screening tool, and a version for health professionals to complete (independent of patients) which allows researchers to operationalize a dyadic approach to analyzing shared decision making. The DCS has been used for measuring decisional needs, tailoring decision support to needs, and evaluating the effect of decision support interventions. It is available in 7 languages (English, French, Dutch, Spanish, German, Japanese, Chinese) with permission granted for translation into 6 other languages.

Of 207 studies that used the DCS, 84 were RCTs, 35 descriptive, 34 pre-/post-test, 13 surveys, 12 scale development, 7 correlational, 4 psychometric evaluations, 4 needs assessments, 4 prospective cohorts, and 10 other. Interventions evaluated in 138 studies were most often patient decision aids (n=97), patient information (n=21), and other (e.g. counseling, interview, consultation, workshops).

Research priorities identified in the workshop were to:

- explore patterns of uncertainty (expected/ desired/temporal), dimensionality of the subscales and total score
- determine a minimal clinically important difference for the clinical version
- evaluate its usefulness as an organizational performance indicator

Finally, there is the need to determine whether or not to re-frame the scale to be positively worded such that the measurement tool would monitor improvement in decisional comfort as opposed to reduction in decisional conflict.

Patient Decision Aids

Patient decision aids are tools that translate research evidence by providing information on the options, benefits, risks and associated probabilities; helping patients clarify their values for outcomes; and providing guidance in the process of decision making. Of 90 randomized controlled trials of patient decision aids identified in the Cochrane review to October 2009, 24 were conducted with decision aids that were developed using the ODSF. Unlike other decision aids in which there is greater variability in content, decision aids based on the ODSF were more likely to include information on options, benefits, harms (100%); probabilities of benefits/harms (100%); an explicit exercise to clarify values (100%); examples of others' experience with decision making (90%); and guidance in the decision making steps (95%). In general, the ODSF decision aids preformed similarly to other decision aids in improving knowledge and expectations, achieving decisions that are congruent with values, reducing decisional conflict, and helping individuals reach a choice.

Research priorities identified in the workshop were to:

- optimize the decision support intervention for the right patient, right time and right dose
- establish reporting standards for components in the decision aid as well as how it was used
- determine effective implementation strategies

Decision Coaching and Training

Recently, the ODSF was merged with the concept of shared decision making to create the Framework for Decision Coach Mediated Shared Decision Making. In this framework, the decision coach implements the ODSF to prepare patients for discussing the decision with their clinician by assessing patients' decisional needs, providing decision aids and/or decision coaching to address known needs, evaluating decision quality, and screening for factors influencing implementation of the decision. Training in 2 RCTs and 1 pre-/post study improved knowledge and skills with coaching simulated patients. Seven RCTs that evaluated coaching within studies of patient decision aids showed that coaching improves satisfaction with the process relative to a decision aid alone, lowers hysterectomy rates and related costs, and improves knowledge relative to usual care (but was not different from decision aids alone for effect on knowledge). To facilitate implementation of decision support in clinical practice, resources that have been developed and validated include: the Ottawa Personal Decision Guide as a decision coaching protocol, training, and the Decision Support Analysis Tool (DSAT-10).

Research priorities identified in the workshop were to:

- create a taxonomy for decision coaching
- determine effective ways to train professionals to support the decision making process
- explore the effect of coaching on clinical encounters and patient outcomes

Conclusions

The ODSF has been extensively validated through decisional needs assessment studies with patients, the public and healthcare professionals. It has been used to develop valid and reliable instruments for measuring decisional conflict and related modifiable factors as well as the quality of decision support provided to patients. Results of RCTs show that decision aids based on the ODSF have similar effects on decision quality compared to other decision aids. Clear research priorities were identified for each of the 5 key areas and interestingly often include implementation as part of routine clinical care.

Workshop Planning Team:

Dawn Stacey (chair), Annette O'Connor, France Legare, Margaret Lawson, Bill Brinkman (US), Jennife Kryworuchko, Liz Drake, Carol Bennett, Sarah Mullan, Debbie Morris, Sara Khangura, Deanne McArthur.

Workshop Participants:

Marie Bakitas (US), Angela Buchholz (Germany), Kate Clay (US), Angela Coulter (UK), Barbara Davies (CA), Sandy Dunn (CA), Carolin Fiege (CA), Val Fiset (CA), Ian Graham (CA), Aubri Hoffman (US), Janet Jull (CA), Jo Lally (UK), Annie LeBlanc (CA), Hilary Llewellyn-Thomas (US), Marie-Chantal Loiselle (CA), Jessie McGowan (CA), MaryAnn Murray (CA), CJ Ng (Malaysia), Andrea Powers (US), Mary Ropka (US), Anton Saarimaki (CA), Rajiv Samant (CA), Mila Urrutia (Chile)