

Recent Advances in Developing Patient Decision Aids to Promote Shared Decision Making

Annette O'Connor RN PhD

Professor, University of Ottawa Faculty of Health Sciences and Faculty of Medicine, CAN

Senior Scientist, Ottawa Health Research Institute

www.ohri.ca

Annotated Bibliography

Books

Edwards A, Elwyn G. Evidence-based Patient Choice. New York: Oxford University Press, 2001. Compilation of chapters by leading authors in U.K. and North America. Issues focus on theory, practice, education, and policy.

Special Issues of Journals Focused on Patient Decision Making (these are gold mines of information on background, reviews of research, conceptual issues, trends).

British Medical Journal- Patients as Partners in Care 1999;vol 319.

Effective Clinical Practice - Patient Decision Making July-August 1999;2(4).

Journal of the National Cancer Institute Monograph- Risk Communication and Decision Making. Number 25, 1999.

MEDLINE indexed Journals that Frequently Publish Articles on Decision Aids (Including Development and Pilot Testing).

Medical Decision Making

Health Expectations

Patient Education and Counseling

Society Meetings with Abstract Categories and Interest Groups in Shared Decision Making

Society for Medical Decision Making

International Society for Technology Assessment in Health Care

Reviews of the Efficacy of Decision Aids and Their Elements

2001

O'Connor A, Rostom A, Fiset V, Tetroe J, Entwistle V, Llewellyn-Thomas H, Holmes-Rovner M, Barry M, Jones J. Decision Aids for Patients Facing Health Treatment or Screening Decisions: A Cochrane Systematic Review. A systematic review and meta-analysis of the randomized trials of decision aids used with actual patients. First published in BMJ. 1999;319:731-734. Recently updated March 2001. See Cochrane library for details, ongoing updates, trials in progress, inventory of existing decision aids. Inventory of aids also available at www.ohri.ca/decisionaid.

Rothert ML, O'Connor AM. Health decisions and decision support for women. Annu Rev Nurs Res 2001;19:207-324. Examines trials of decision aids focused on women's issues.

Estabrooks C, Goel V, Thiel E, Pinfold P, Sawka C, Williams I. Decision aids: are they worth it? A systematic review. J Health Serv Res Policy 2001;6(3):170-182.

2000

Edwards AGK, Hood K, Matthews EJ, Russell D, Russell IT, Barker J, and et al. The effectiveness of one-to-one risk communication interventions in health care: a systematic review. Med Decis Making. 2000;20:290-297. Focus on risk communication, and important component of decision aids.

Molenaar S, Sprangers MAG, Postma-Schuit FCE, Rutgers EJT, Noorlander J, Hedriks J, De Haes HCJM. Feasibility and effects of decision aids. Med Decis Making. 2000;20(1):112-127. Describes observational and trials of decision aids. Studies organized historically to demonstrate progress and trends.

Annotated Bibliography of Shared Decision Making

1999

Bekker H, Thornton JG, Airey CM, Connelly JB, Hewison J, Robinson MB, Lilleyman J MacIntosh M, Maule AJ, Michie S, Pearman AD. Informed decision making: as annotated bibliography and systematic review. *Health Technology Assessment* 1999;3(1). Copies of executive summary available from National Coordinating Center for Health Technology Assessment in UK web site <http://www.hta.nhsweb.nhs.uk> –a very thorough review methodology on website.

O'Connor AM, Fiset V, DeGrasse C, Graham I, Evans W, Stacey D, Laupacis A, Tugwell P. Decision aids for patients considering health care options: Evidence of efficacy and policy implications. *J Natl Cancer Inst. Monograph No 25*, 1999;67-80. Broad overview of decision aids commissioned by the US NCI-includes non-cancer studies as well and points to gaps, methods issues, policy issues.

Situations requiring decision aids

Forthcoming from U.S. Preventive Task Force: Guidelines on shared decision making when discussing preventive options. With the revised rating system, "C" class recommendations will focus exclusively on 'close call' decisions or those sensitive to patient preferences. The role of clinicians in counseling regarding these and other classes of recommendations is currently being debated.

Eddy DM. *A Manual for Assessing Health Practices & Designing Practice Policies The Explicit Approach*. Philadelphia: American College of Physicians. 1992. Distinguishes between standards, guidelines, and options, definitions useful in identifying when decision aids are appropriate.

American College of Physicians. Guidelines for counselling postmenopausal women about preventive hormone therapy. *Ann Intern Med*. 1992;117(12):1038-41. An example of a practice guideline in which assessing patient preferences is recommended in determining optimal treatment strategy.

Kassirer JP. Incorporating patients' preferences into medical decisions. *N Engl J Med*. 1994;330(26):1895-6. Raises important issue re when a patient preferences need to be incorporated in medical decision making.

Conceptual Frameworks of Providing Decision Support for Patients

Prescriptive Frameworks that start with **Expected Utility Maximization** to Guide Decision Making

Dowie J. What decision analysis can offer the clinical decision maker. Why outcome databases such as KIGS and KIMS are vital sources for decision analysis. *Hormone Research*. 1999;51 Suppl 1:73-82.

Pauker S and Pauker S. What is a good decision? *Effective Clinical Practice*. 1999;2(4): 195-197. See also Pauker SP, and Pauker SG. The amniocentesis decision: Ten years of decision analytic experience. *Birth Defects*. 1987;23(2):151-69.

Sox H. What is a good decision? *Effective Clinical Practice*. 1999;2(4):197.

Descriptive Frameworks that Use Expectations and Values and other Determinants of Decision Making Behaviour to Structure Decision Support

Fischhoff B. What do patients want? Help in making effective choices. *Effective Clinical Practice - Patient Decision Making* July-August 1999;2(4):199

Llewellyn-Thomas, H. Presidential Address. *Med Dec Making*. 1995;15(2):101-6. A framework for understanding the factors that influence decisions and preferences, placed in a broader sociopolitical context. Very good for distinguishing between preferences for outcomes, time, treatments, control in decision making etc.

Mulley A. Outcomes research: Implications for policy and practice. In: Smith R, Delamother T, editors. *Outcomes in Clinical Practice*. London: BMJ Publishing Group. 1995:13-27. Foundation for Informed Medical Decision Making approach. Focus on outcomes research.

Annotated Bibliography of Shared Decision Making

O'Connor AM, Tugwell P, Wells GA, Elmslie T, Jolly E, Hollingworth G, McPherson R, Bunn H, Graham I, Drake E. A decision aid for women considering hormone therapy after menopause: Decision support framework and evaluation. *Patient Edu Counsel.* 1998;33(3):267-279. Ottawa Framework defines personal and environmental determinants of decisions that may be sub-optimal, decision support interventions tailored to determinants, and potential effects on decision making and outcomes of decisions. See also www.LRI.CA

Research Triangle Institute. Consumer health informatics and patient decision-making. (AHCPR Pub. No. 98-N001). Agency for Health Care Policy and Research: Prepared by James Hersey Jennifer Matheson and Kathleen Lohr at the **Research Triangle Institute**. 1997. The framework has a strong health services research perspective.

Rothert ML, Holmes-Rovner M, Rovner D, Kroll J, Breer L, Talarczyk G, Schmitt N, Padonu G, Wills C. An educational intervention as decision support for menopausal women. *Research in Nursing and Health.* 1997;20:377-387. From **Michigan State University**. Framework centers on the role of information and values.

Transactional Frameworks that Describe Patient and Practitioner Roles in Shared Decision Making

Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: What does it mean? *Soc Sci Med.* 1997;44:681-692. See also *BMJ.* 1999; 319: 780-2. **McMaster Approach**. Useful examination of what constitutes shared decision making.

Entwistle VA, Sowden AJ, Watt IS. Evaluating interventions to promote patient involvement in decision making: By what criteria should effectiveness be judged? *J Health Serv Res Policy.* 1998; 3(2):100-7. From the **University of Aberdeen, UK**. Illustrates that evaluation criteria depend in part on the the type of involvement of the patient and practitioner. For an examination of the **ethical underpinnings** of informed choice, see also: Entwistle VA, Sheldon TA, Sowden A, Watt IS. Evidence-Informed patient choice. *Int J Technol Assess Health Care.* 1998;14:2.

Rothert M, Talarczyk GJ. Patient compliance and the decision making process of clinicians and patients. *J Compliance Health Care* 1987;2:55-71. From **Michigan State University**. Describes the mutual roles of patients and practitioners and the central role of information and values.

Measures for Evaluating Decision Aids

Overview of issues and measures:

See essays written by several leading authorities on defining "a good decision" in *Effective Clinical Practice* 1999;2(4):163-170.

Edwards A, Elwyn G. How should 'effectiveness' of risk communication to aid patients' decisions be judged? A review of the literature. *Med Decis Making* 1999; 19(4):428-34. Describes the measures used in published studies including cognitive, affective, and behavioural measures.

Entwistle VA, Sowden AJ, Watt IS. Evaluating interventions to promote patient involvement in decision making: By what criteria should effectiveness be judged? *J Health Serv Res Policy.* 1998; 3(2):100-7. Excellent discussion of evaluation issues.

Holmes Rovner M, Rovner D. Measuring Improved Patient Choice. *Journal of Evaluation and Clinical Practice.* 2000;6(3):263-272. Discusses the issue of how to operationalize one criterion of good decisions "consistent with patient values". Compares and contrasts the use of correlations between: a) choices and subjective expected utility; and b) choices and expected utility.

O'Connor AM, Fiset V, DeGrasse C, Graham I, Evans W, Stacey D, Laupacis A, Tugwell P. Decision aids for patients considering health care options: Evidence of efficacy and policy implications. *J Nat Cancer Inst. Monograph No 25,* 1999 p.67-80. Refers to some of the measures used to evaluate decision aids and discusses the issue of measuring efficacy.

O'Connor A, Llewellyn-Thomas H, Sawka C, Pinfold S, To T, Harrison D. Physicians' opinions about decision aids for patients considering systemic adjuvant therapy for axillary-node negative breast cancer. *Patient Edu Counsel.* 1997;30:143-53. Describes criteria for evaluation that would convince a random sample of oncologists that a decision aid was 'effective'.

Annotated Bibliography of Shared Decision Making

Decisional Conflict

Practitioner: Dolan, J.G., Markakis, K.M., Beckman, H.B., & Gleeson, M.L. Further evaluation of the provider decision process assessment instrument (PDPAI): a process-based method for assessing the quality of health providers' decisions (abstract). *Med Decis Making*. 1996; 16(4), 465. Tool to assess practitioner's decisional conflict, based on one developed by O'Connor for patients.

Patient: O'Connor, A. M. Validation of a Decisional Conflict Scale. *Med Decis Making*. 1995; 15(1), 25-30. **Keywords:** decisional conflict scale; conceptual framework decisional conflict; 16 items; 3 subscales: uncertainty Re decision; factors contributing to uncertainty; perceived effective decision making; test-retest 0.81; internal consistency 0.78-0.92; discriminant validity high; population immunization , breast screening. See also: Bunn H, O'Connor AM. Validation of client decision making instruments in the context of psychiatry. *Can J Nurs Res* 1996;28(3):13-27. See website at WWW.OHRI.CA/programs/clinical_epidemiology/ohdec/measures for most up to date versions, and applications to several populations.

Decision Making Style, Preference

Degner L, Sloan JA, Venkatesh P. The control preferences scale. *Can J Nurs Res*. 1997;29(3):21-43. Overview of a measure used to elicit preferences for participation in decision making.

Kaplan, S. H., Greenfield, S., Gandek, B., Rogers, W. H., & Ware, J. E. Characteristics of physicians with participatory decision-making styles. *Ann Intern Med*. 1996;124(5), 497-504.

Krantz, D.S., Baum, A., & Wideman, M.V. Assessment of preferences for self-treatment and information in health care. *Journal of Personality and Social Psychology*. 1980;39:977-990. **Keywords:** decision aid tool; Krantz Health Opinion Survey; preferences for Tx approaches; two subscales; measure preferences for information and for behavioural involvement in medical care; validity: construed, criterion, discriminant; reliability: test-retest.

Lerman, C.E., Brody, D.S., Caputo, G.C., Smith, D.G., Lazaro, C.G., & Wolfson, H.G. Patients' Perceived Involvement in Care Scale: relationship to attitudes about illness and medical care. *J Gen Intern Med*. 1990;5:29-33. **Keywords:** decision aid tool; perceived involvement in care scale; attitudes to illness and management of illness (Dr. facilitation of patient involvement, level of info exchange; participation in decision making) ; reliability/validity; internal consistency; .

Pierce PF. The influence of sociodemographic factors and decision style on African-American women's breast cancer treatment choices. Paper presented at the 21st annual Meeting of the Society for Medical Decision Making, Reno, Nevada, October 3-6, 1999.

Strull WM, Lo B, Charles G. Do patients want to participate in decision making? *JAMA*. 1984;252:2990-4. Describes a measure for eliciting preferences for participation in decision making.

Decision Regret

O'Connor A. et al. *Medical Decision Making* 2001. Nov/Dec/ Abstracts section. 5 item scale. Cronbach's alpha coefficient 0.92. Regret scores correlate with health outcomes, satisfaction with decision making. Scale discriminates between passive and active involvement in decision making & shows trend in discriminating between decision supporting interventions in those changing the status quo.

Informed Choice

Marteau TM, Dormandy E, Michie S. A measure of informed choice. *Health Expect* 2001;4(2):99-108. 8 item scale of knowledge of antenatal screening, 4 item scale of attitudes toward undergoing screening test, and record of test uptake. Alpha 0.82-0.83.

Satisfaction with decisions, decision making

BarryMJ, Cherkin DC, Chang Y, Fowler FJ, Skates S. A randomized trial of a multimedia shared decision-making program for men facing a treatment decision for benign prostatic hyperplasia. *DMCO*, 1997; 1(1):5-14. Describes the Decision Satisfaction Inventory tool in detail. Measures satisfaction with decision making process and with decision.

Guyatt, G. H., Mitchell, A., Molloy, D. W., Capretta, R., Horsman, J., Griffith, L. Measuring patient and relative satisfaction with level of aggressiveness of care and involvement in care decisions in the context of life threatening illness. *Journal of Epidemiology* 1995;48:1225-1224. **Keywords:** decision aid tool; indices; patient satisfaction index (23 items) which measures

Annotated Bibliography of Shared Decision Making

patient and relative satisfaction with aggressiveness of Tx and degree of participation in decision making; relative of competent patient satisfaction index (34 items); relative of incompetent patient satisfaction index (29 items); 102 elderly patients and 153 relatives, recruited 8 nursing homes; intraclass correlations 0.86-0.94; correlations with global ratings high (0.59-0.75)

Hollen, P.J. Psychometric properties of two instruments to measure quality decision making. *Res Nursing Health*. 1994;17:137-148. **Keywords:** decision aid tool; decision making quality scale, (DMQS) version x2 (self and other); decision making quality inventory; (DMQI) (version V2- teens, parents); conceptual basis; Janes and Mann conflict model; DMQS 7 criteria; canvassing of alternatives and objectives; evaluation of consequences; search for info; unbiased assimilation of new info; reevaluation of consequences; planning for implementation contingencies, (7 items); DMQI decision making style (5 types) through 6 stages of decision making (24 items), acceptability, reliability, content validity described.

Holmes-Rovner, M., Kroll, J., Rotherert, M. L., Schmitt, N., Rovner, D. R., Breer, L., Padonu, G., & Talarczyk, G. Patient satisfaction with health care decisions. *The Satisfaction with Decision Scale*. *Med Decis Making*. 1996;16(1):58-64. **Keywords:** decision aid tool; satisfaction with decision tool; global satisfaction with decision and 3 attributes of effective decision; differentiates satisfaction with decision from satisfaction with provider, desire to participate in decision; 6 items; 250 women hormone replacement therapy; feasibility high; correlation with decisional conflict scale / confidence in decision scale.

McCusker, J. Development of scales to measure satisfaction and preferences regarding long-term and terminal care. *Med Care*. 1984;22:476-493. **Keywords:** decision aid tool; measuring attitudes toward medical care of chronically and terminally ill patients and families; conceptual framework: Breslau twelve scales, three versions; (internal consistency, discriminant validity, convergent validity) evaluated for each scale.

Sainfort F, Booskie B. Measuring post-decision satisfaction. *Med Decis Making*. 2000;20:51-61. Decision attitude scale was evaluated in the context of health plan choices.

Sutherland, H. J., Lockwood, G. A., Minkin, S., Tritchler, D. L., Till, J. E., & Llewellyn-Thomas, H. A. Measuring satisfaction with health care: a comparison of single with paired rating strategies. *Soc Sci & Med*. 1989;28:53-58. **Keywords:** decision aid tool; comparisons of 2 techniques of measuring patient satisfaction with health care; paired comparisons; ratings on VAS; breast cancer patients; test-retest reliability; convergent reliability.

Roberts, C. S., Cox, C. E., Reintgen, D. S., Baile, W. F., & Gilbertini, M. Influence of physician communication on newly diagnosed breast patients' psychologic adjustment and decision- making. *Cancer*. 1994;74:336-341. **Keywords:** decision aid tool; cancer diagnostic interview scale; patient perception of surgeon behaviour; info-giving or interpersonal; 18 items; internal consistency