Annotated Bibliography: Studies Evaluating Decision-Support Interventions for Patients

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A complete version, including search strategy, synopsis, and abstracts, is available on the World Wide Web: http://www.lri.ca

Keywords describe target population, decision, decision-support intervention, method of delivery, study design, sample, and results. Results are classified according to the following criteria for evaluation and (codes):

- intervention's feasibility, comprehensibility, length, balance, clarity, amount of information, acceptability, usefulness in decision making; holds interest; recommend to others; coded as (either positive, negative, neutral, or mixed)
- impact of decision support on patients' knowledge, satisfaction with decision making, satisfaction with decision support, satisfaction with care, decisional conflict, uncertainty, feeling informed, having clear values, perceived effective decision making, having realistic expectations, anxiety, involvement in decision making, decision congruence with values, self-efficacy, decision making skills, quality of life, utilization of resources, costs, psychological adaptation, persistence with decision, and health outcomes (coded as increased, decreased, unchanged, or mixed in pretest/posttest studies; or positive, negative, neutral in posttest only studies; or difference no difference in comparative studies)

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- impact of decision support on decision (coded as unchanged, changed, mixed, other, including direction where applicable)
- Barry, M.J., Fowler, F.J. Jr., Mulley, A.G. Jr., Henderson, J.V. Jr., & Wennberg, J.E. (1995). Patient reactions to a program to facilitate patient participation in treatment decisions for benign prostatic hyperplasia. *Medical Care*, 33, 771–782. **Keywords**: benign prostatic hyperplasia; surgery vs. watchful waiting; shared decision making program; interactive videodisc; posttest survey; 373 male patients at point of decision; length positive; balance positive; clarity positive; amount information positive; acceptability positive; usefulness positive; value congruence positive.
- Beck, A., Barrett, P. Jr., O'Neill, M., Sharp, M., & Fieger, H. Jr. (1994). Evaluation of a low back pain shared decision-making program (abstract). AHSR & FHSR Annual Meeting Abstract Book, 11, 10. Keywords: low back pain; lumbar laminectomy vs. no surgery; shared decision making program; interactive videodisc; pretest posttest; 84 patients at point of decision; comprehensibility positive; length positive; hold interest yes; recommended to others yes; balance mixed response; amount of information positive; acceptability positive; knowledge increased; decision changed toward having surgery.
- Boberg, E.W., Gustafson, D.H., Hawkins, R.P., Chan, C-L., Bricker, E., Pingree, S., & Berhe, H. (1995). Development, acceptance, and use patterns of a computer-based education and social support system for people living with AIDS/HIV infection. *Computers in Human Behavior*, 11(2), 289–311. **Keywords:** AIDS/HIV; general approach to assist problem solving; CHESS decision support module; computer; posttest survey; 116 HIV infected men and women who may or may not have been making decisions; utilization of decision support mixed because most users not making decisions.
- Brennan, P.F., Ripich, S., & Moore, S.M. (1991). The use of home-based computers to support persons living with AIDS/ARC. *Journal of Community Health Nursing*, 8(1), 3–14. **Keywords**: HIV/AIDS; general approach to assist problem solving; home-based computer network; posttest survey; 15 persons with AIDS who may or may not be at point of decision; holds interest positive; utilization of decision aid mixed.
- Chapman, G.B., Elstein, A.S., & Hughes, K.K. (1995). Effects of patient education on decisions about breast cancer treatments: A preliminary report. *Medical Decision Making*, 15(3), 231–239. **Keywords**:

breast cancer; surgery a) lumpectomy plus radiation, b) mastectomy followed by breast reconstruction, c) mastectomy followed by breast prosthesis; shared decision making program; video vs. booklet delivery; quasiexperiment; 82 female university students; knowledge increased for both interventions; preference for lumpectomy increased in video viewing group.

- Clancy, C.M., Cebul, R.D., & Williams, S.V. (1988). Guiding individual decisions: A randomized, controlled trial of decision analysis. *American Journal of Medicine*, 117, 53–58. **Keywords:** health care workers at risk for Hepatitis B exposure; to take or not take Hep B vaccine; general information re benefits risks vs. general information plus individualised decision analysis vs. control; paper delivery via mail; RCT; 1280 medical faculty and residents who may have been making decision; decision to be immunized greater in individualized decision analysis group; decision congruence with expected values increased in individualized decision analysis group.
- Deber, R., Kraetschmer, N., & Trachtenberg, J. (1994). Shared decision making: How does one measure success? (abstract) *Medical Decision Making*, 14(4), 429. **Keywords:** benign prostatic hyperplasia; surgical vs. non-surgical alternatives; shared decision making program; interactive videodisc; pretest posttest 190 male patients at the point of decision; length positive; balance positive; clarity positive; amount of information positive; acceptability positive; positive effect on practitioner-patient relationship, knowledge increased; perceptions of effect on decision mixed.
- Dolan, J.G. (1995). Are patients capable of using the analytic hierarchy process and willing to use it to make clinical decisions? *Medical Decision Making*, *15*(1), 76–80. **Keywords:** high risk for colon cancer; participation in colon cancer screening program; analytic hierarchy decision support; computer; pretest posttest; 20 healthy volunteers; feasibility positive; influence on decision mixed.
- Fetting, J.H., Siminoff, L.A., Piantadosi, S., Abeloff, M.D., Damron, D.J., & Sarsfield, A.M. (1990). Effect of patients' expectations of benefit with standard breast cancer adjuvant chemotherapy on participation in randomized clinical trial: A clinical vignette study. *Journal of Clinical Oncology*, 8(9), 1476–1482. **Keywords:** breast cancer; clinical trial participation; chances of benefit described qualitatively or quantitatively in vignette; 282 female cancer patients not at point of decision making; RCT comparing 2 versions; decision to participate

- in trial higher is greater in group receiving qualitative information; effects on realistic expectations mixed.
- Greenfield, S., Kaplan, S., & Ware, J.E. (1985). Expanding patient involvement in care: Effects on patient outcomes. *Annals of Internal Medicine*, 102, 520–528. **Keywords:** outpatients with gastric ulcers; active involvement in discussion with physician; patients coached to ask questions and negotiate medical decisions; RCT comparing decision support with usual care control; 45 outpatients with ulcers not necessarily at point of decision; personal counselling; patient-practitioner relationship positive; satisfaction with care positive; involvement in decision making increased; decision making skills increased; quality of life increased.
- Greenfield, S., Kaplan, S.H., Ware, J.E. Jr., Yano, E.M., & Frank, H.J. (1988). Patients' participation in medical care: Effects on blood sugar control and quality of life in diabetes. *Journal of General Internal Medicine*, 3, 448–457. **Keywords:** diabetes; active involvement in discussion with physician; patients coached to ask questions and negotiate medical decisions; personal counselling; RCT comparing decision support with standard education; 73 patients on insulin pump; knowledge no difference; satisfaction with care no difference; involvement in decision making increased with decision support; decision support group had better decision making skills, improved quality of life, less change in treatment regimens and improved health outcome HBA1.
 - Gustafson, D., Wise, M., McTavish, F., Taylor, J.O., Wolberg, W., Stewart, J., Smalley, R.V., & Bosworth, K. (1993). Development and pilot evaluation of a computer-based support system for women with breast cancer. *Journal of Psychosocial Oncology*, 11(4), 69–93. **Keywords:** breast cancer; mastectomy versus lumpectomy plus radiation; CHESS decision support module; computer; posttest survey; 30 women with breast cancer who may or may not be making decisions; utilization mixed because most had already made decision.
 - Holmes-Rovner, M., Rovner, D., Kroll, J., Rothert, M., Padonu, G., & Talarczyk, G. (1995). Does decision support make people more rational? (abstract) *Medical Decision Making*, 15(4), 418. **Keywords:** perimenopausal women; hormone replacement therapy or not; active decision support vs. brochure vs. lecture/discussion; delivery variable; RCT of three interventions; 189 perimenopausal women who may or not be making decisions; expected values more congruent with decision in group receiving active decision support.

- Kroll, J.C., Rothert, M.L., Rovner, D.R., Holmes-Rovner, M., Schmitt, N. Padonu, G.B., Talarczyk, G., & Breer, M.L. (1994). Decision support intervention: More is not necessarily better (abstract). *Medical Decision Making*, 14(4), 440. **Keywords:** perimenopausal women; hormone replacement therapy or not; active decision support vs. brochure vs. lecture/discussion; delivery variable; RCT of three interventions; 189 perimenopausal women who may or not be making decisions; all groups improved knowledge, self-efficacy, and reduced uncertainty; no difference between groups.
- Levine, M.N., Gafni, A., Markham, B., & MacFarlane, D. (1992). A bedside decision instrument to elicit a patient's preferences concerning adjuvant chemotherapy for breast cancer. *Annals of Internal Medicine*, 117, 53–58. **Keywords:** breast cancer; adjuvant chemotherapy or not; decision board; personal counselling; posttest survey; 30 healthy volunteers & 37 breast cancer patients; acceptability positive; comprehensibility positive; usefulness/helpfulness positive; decisions stable on retest in volunteer group.
- Liao, L., Jollis, J.G., DeLong, E.R., Peterson, E.D., Morris, K.G., & Mark, D.B. (1996). Impact of an interactive video on decision making of patients with ischemic heart disease. *Journal of General Internal Medicine*, 11(6), 373–376. **Keywords:** ischemic heart disease; medical therapy vs. angioplasty vs. bypass surgery; shared decision making program; interactive videodisc; pretest posttest; 60 patients at point of decision; usefulness positive; influence on decision mixed; anxiety decreased.
- Llewellyn-Thomas, H.A., Thiel, E.C., McGreal, M.J., & Sem, F.W.C. (1992). Do interactive computer programs to present clinical trial information affect the trial entry decision? (abstract) *Medical Decision Making*, 12(4), 342. **Keywords:** cancer patients; clinical trial participation; mode of info delivery 1) interactive 2) computerized 3) standard tape-recorder; RCT of delivery methods; 100 cancer patients making hypothetical decision; knowledge no diff; satisfaction with decision support no difference; willingness to participate in clinical trial more likely with computer group.
 - Maisels, M.J., Haynes, B., & Conrad, S. (1983). Circumcision: The effect of information on parental decision making. *Pediatrics*, 71, 453–455. **Keywords:** newborns; circumcision or not; prenatal information on options, risks, benefits; written information; RCT compared to no information; parents of 51 male infants; knowledge no difference; decision no difference.

- O'Connor, A., Tugwell, P., Wells, G., & Elmslie, T. (1995). Do decision aids help postmenopausal women considering preventive hormone replacement therapy (HRT) (abstract). *Medical Decision Making*, 15 (4), 433. **Keywords:** postmenopausal women; hormone replacement therapy or not; tailored decision aid versus general educational pamphlet; audio booklet versus pamphlet; Phase 1 pretest posttest 100 postmenopausal women; knowledge and realistic expectations increased; decisional conflict decreased; Phase 2 RCT of 100 women; decision aid group had less decisional conflict particularly in areas of feeling informed, clear about values, and supported in decision making; decisions no difference.
- O'Connor, A.M., Pennie, R.A., & Dales, R.E. (1996). Framing effects on expectations, decisions, and side effects experienced: The case of influenza immunization. *Journal of Clinical Epidemiology*, 49(11), 1271–1276. **Keywords:** patients high risk for complications of influenza; to have the 'flu vaccine or not; decision support framing benefits/risks either positively or negatively; personal counselling with poster; RCT comparing frames of information; 292 unimmunized cardiac and respiratory patients at decision point; decision no difference; decisional conflict no difference; expectations of side effects more realistic among positive frame group; reported side effects lower among positive frame group.
- Oppenheim, P.I., Sotiropoulos, G., Baraff, L.J. (1994). Incorporating patient preferences into practice guidelines in management of children with fever without source. *Annals of Emergency Medicine*, 24, 836–841. **Keywords:** children with fever; choice of 2 management strategies; information on options, benefits, risks and costs; personal review of written scenarios; posttest survey; 103 parents of children with fever making hypothetical decision; knowledge positive; decisions mixed.
- Owens, R.G., Ashcroft, J.J., Leinster, S.J., & Slade, P.D. (1987). Informal decision analysis with breast cancer patients: An aid to psychological preparation for surgery. *Journal of Psychosocial Oncology*, *5*, 23–33. **Keywords:** breast cancer; mastectomy vs. lumpectomy; decision analysis based on perceived probabilities and values; personal counselling; pretest-posttest; 43 women at the point of decision; usefulness/helpfulness positive; psychological adaptation increased; value congruence with decision positive.
- Quaid, K.A., Faden, R.R., Vining, E.P., & Freeman, J.M. (1990). Informed consent for a prescription drug: Impact of disclosed information on patient understanding and medical outcomes. *Patient Education and*

- Counselling, 15, 249–259. **Keywords:** patients with epilepsy; to take antiepileptic or not; variation in information disclosure (reasonable person verus medical practice standards); written materials; RCT; 43 adult patients at decision point; anxiety no difference; knowledge no difference; more physical problems with medical practice standard; patient adherence no difference.
- Reinders, M., & Singer, P.A. (1994). Which advance directive do patients prefer? *Journal of General Internal Medicine*, 9, 49–51. **Keywords:** outpatients; end of life decision; Let Me Decide directive 43 pg booklet vs. Medical Directive 6 pg pamphlet; posttest survey; 97 outpatients; acceptability no difference.
- Schonwetter, R.S., Walker, R.M., Kramer, D.R., & Robinson, B.E. (1993). Resuscitation decision making in the elderly: The value of outcome data. *Journal of General Internal Medicine*, 8, 295–300. **Keywords:** seniors; CPR end of life; CPR information; personal counselling; pre-post test; 102 seniors over 62 years making hypothetical choices; knowledge unchanged; preferences for CPR changed.
- Sebban, C., Browman, G., Gafni, A., Norman, G., Levine, M., Assouline, D., & Fiere, D. (1995). Design and validation of a bedside decision instrument to elicit a patient's preference concerning allogeneic bone marrow transplantation in chronic myeloid leukemia. *American Journal of Hematology, 48*, 221–227. **Keywords:** chronic myeloid leukemia; bone marrow transplantation vs. conservative mgt; decision board; post-test; 42 healthy hospital personnel making hypothetical decision; feasibility positive; comprehensibility positive; length positive; clarity positive; amount of information positive; preferences stable on retest; satisfaction with decision positive.
- Street, R.L., Voigt, B., Geyer, C., Manning, T., & Swanson, G.P. (1995). Increasing patient involvement in choosing treatment for early breast cancer. *Cancer*, 76(11), 2275–2285. **Keywords:** breast cancer; mastectomy versus lumpectomy with radiation; interactive multimedia program versus brochure; RCT; 60 patients at the point of decision; knowledge increased in both groups but not significantly between groups; involvement in decision making not different.
- The SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *Journal of the American Medical Association*, 274(20), 1597–1598. **Keywords:** seriously ill hospitalized patients;

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end of life decisions; attending physicians received prognostic information and nurses had multiple contacts with team and families to provide information, elicit preferences, and facilitate communication; mixed delivery; RCT including usual care control; 4,804 patients and families; DNR decisions unchanged; no difference in: patient practitioner communication, physicians' knowledge of patients' preferences, length of stay, health outcomes.

- Van Ruiswyk, J., Griffin, R., & Schapira, M. (1995). Informing patients about prostate cancer screening risks (abstract). *Medical Decision Making*, 15(4), 421. **Keywords:** adult males; prostate cancer screening participation; pamphlet describing risks and benefits vs. augmented pamphlet including false positive and negative rates; RCT; 136 male patients at decision point; knowledge increased both groups but no difference between groups; decision not significantly different between groups.
- Wagner, E.H., Barrett, P., Barry, M.J., Barlow, W., & Fowler, F.J. Jr. (1995). The effect of a shared decision making program on rates of surgery for benign prostatic hyperplasia. Pilot results. *Medical Care*, 33 (8), 767–770. **Keywords:** benign prostatic hyperplasia; surgery versus watchful waiting; shared decision making program; interactive videodisc; pre-post test; 406 males at point of decision; change in decision leaning towards watchful waiting.
- Wolf, A.M.D., Narsen, J.F., Wolf, A.M., & Schorling, J.B. (1996). The impact of informed consent on patient interest in prostate-specific antigen screening. *Archives of Internal Medicine*, 156(2), 1333–1336. **Keywords:** adult males; participation in screening for prostate cancer; scripted information on benefits, risks, decision vs. single sentence; RCT; 205 males at point of decision; decision changed with more information they were less willing to participate in screening.