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# Kit helps physicians, women work together to weigh HRT risks, benefits

**Alex Robinson**

In Brief

THE OTTAWA HEALTH DECISION CENTRE IS DEVELOPING A LINE OF DECISION AIDS to make it easier for physicians to discuss potential therapies with patients. The first kit, *Making choices: hormones after menopause,* helps women weigh the risks and benefits of hormone replacement therapy.

En bref

LE CENTRE DE DÉCISIONS DE TRAITEMENTS EN MATIÈRE DE SANTÉ D'OTTAWA est en train de créer tout un éventail d'aides à la décision pour aider les médecins à discuter de thérapies possibles avec des patients. La première trousse, *Les choix en matière d'hormonothérapie de remplacement,* aide les femmes à peser les risques et les avantages de l'hormonothérapie de remplacement.

The Ottawa Health Decision Centre is developing a line of decision aids to make it easier for physicians to discuss therapies with patients. The first kit, *Making choices: hormones after menopause*, helps women weigh the risks and benefits in deciding whether to take hormone replacement therapy (HRT). (The centre comprises investigators from the University of Ottawa, most of whom are also affiliated with the Clinical Epidemiology Unit of the Ottawa Civic Hospital Loeb Research Institute. It is funded by the Medical Research Council of Canada [MRC].)

Dr. Annette O'Connor says informed-choice kits are for use when "the right course of treatment is not clear, where there's a value-laden component and not everybody agrees that the benefits outweigh the risks. . . . Clinician judgement and patient input on preference are required."

O'Connor, who holds a PhD in medical science, is a senior investigator at the Ottawa Civic Hospital Loeb Medical Research Institute and an associate professor in the University of Ottawa's School of Nursing. She holds a joint appointment to the Department of Epidemiology in the Faculty of Medicine.

She has built her career on the study of decision-making and patient preferences, a field she describes as a growth area. "The consumer movement, including the patient-empowerment movement, has captured the imagination of practitioners and patients," she says. "There's a growing realization that not everything we do is cut and dried. New practice guidelines show grey areas where there are needs for both clinician judgement and patient preference."

*Making choices: hormones after menopause* was released last summer following 2 years' work by O'Connor and an 11-member team from the university and the research centre. Kits on anticoagulant therapy for atrial fibrillation, the treatment of lung cancer and knee injuries, genetic screening, bone-marrow transplants and musculoskeletal pain management will be available within a few years. Funding for the research, $1 million over 5 years, is provided by the Institute for Clinical Evaluative Sciences in Ontario (ICES), Health Canada and the MRC.

## How to order

Practitioners' kits are being sold by the Ottawa Health Decision Centre at a not-for-profit rate of $30 (plus shipping, handling and taxes).

Included are a manual, prescription algorithm, 2 women's take-home kits and 20 extra worksheets. To order the kit, call 888 240-7002 (toll-free); (fax) 613 761-5492.

The HRT kit, which contains material for both physician and patients, is the base model. The physician manual reviews scientific evidence on treatment options and includes an algorithm for tailoring therapy and a follow-up surveillance strategy. The patient receives a take-home kit that includes a 40-minute audio tape, a booklet and a summary worksheet. The audio tape guides the patient through the booklet, which discusses common health problems after menopause as well as the benefits and risks of HRT.

## Six-step process

After working through the booklet the patient completes the six steps on the summary worksheet, which weigh the therapy's risks and benefits. The steps are the heart of the kit and become the focal point for a follow-up consultation.

The first step charts risks and benefits. On the benefit side, the patient charts risks for heart disease and osteoporosis, as well as her need for relief from the effects of menopause. On the risk side, she identifies risk factors for breast cancer, charts her hormonal history and reviews the therapy's contraindications. "Potential risks and benefits can be verified with the physician during the follow-up visit," O'Connor says.

Next the patient assigns values to each benefit and risk by colouring a personal "weigh scale." A glance at this tells the physician what the woman sees as important factors in making her decision.

Team members (from left) are (seated) Gary Hollingworth, Elizabeth Drake, Helen Bunn; (standing) Annette O'Connor, Tom Elmslie, Elaine Jolly, Andreas Laupacis, Ian Graham. Missing are Ruth McPherson, George Wells and Peter Tugwell.

The third step reviews the actions the patient takes to promote the health of her bones, heart and breasts, highlighting points that require counselling. It looks at factors such as exercise habits, weight, stress, whether the patient is lowering her intake of dietary fat, caffeine or alcohol, whether she smokes, the calcium she is taking and whether she has had a mammogram.

In the fourth step the patient lists questions she has about the decision. The fifth helps the woman choose the role she wants to play in deciding whether to use HRT. "She may want the practitioner to decide. She may want a shared decision. She may want to reach the decision after considering her practitioner's opinion." If the choice is the physician's, O'Connor suggests that "the practitioner will adopt more an advisory role with informed consent. If it's shared, there will be more discussion."

The sixth step gauges the patient's interest in taking the therapy. It identifies women with polarized opinions and those who are uncertain.

Before the kit was released, 500 women participated in a focus group on HRT and another 500 women pilot tested a prototype kit. About 85% found the kit balanced; the remainder found it biased in favour of HRT, largely because it raised the therapy as an issue.

O'Connor says women who choose hormone therapy place greater emphasis on its benefits. They usually are at higher risk for heart disease or osteoporosis, or are experiencing significant menopausal symptoms. Those who decline therapy fear its risks and often don't have a good reason for turning to it.

The team's studies show that women learn a great deal from the kits and consequently have more realistic expectations about the risks and benefits of HRT.

Close to 90% of women want their physician to give them information about the therapy. "They want information from other sources, but obviously their physician is the centre of this whole debate," O'Connor says. Most women prefer shared decision-making, "and that's across all age and educational groups, although it is higher for the better educated and the younger women."

The kit was tested on 15 physicians. They liked it, says O'Connor, because it prepared women for decision-making and streamlined the decision process. The kit provides more than informed consent, since it involves the patient in the decision-making process. "Of course, the physician has to believe in shared decision-making," she adds.

The consequences of the conventional alternative — the physician recommends and the patient is expected to follow through — highlight both women's uncertainty about the therapy and their difficulty managing it. O'Connor points to a study showing that about a quarter

of women prescribed HRT don't fill their prescriptions; of those who do, one-fifth stop taking it within 9 months.

"Having the decision-making up front may result in a higher initial refusal rate but it also offers a good opportunity to promote other health practices in those who decline the therapy," O'Connor says. "And it may promote better longer-term commitment in the women who choose the therapy. We're evaluating this possibility right now in a study we're doing here in Ottawa."

The team is also using a relatively new method of summarizing clinical trials and a decision-support algorithm the centre has developed.

The new summary method is meta-analysis, the specialty of the editorial review teams within the Cochrane Collaboration. Two collaborators, Drs. Peter Tugwell and George Wells, are also part of the centre team. "Basically, what the Collaboration does is summarize the evidence of clinical studies and translate it for the practitioner and the patient," says O'Connor. It is an added plus that the Collaboration updates the evidence as new trials are completed, so that information in the kit can be altered to reflect the latest evidence.

The value of using pooled information showed clearly when the first kit's estimate for breast-cancer risk didn't shift with either of two conflicting studies published in 1995. The link with the Collaboration also helps the Health Decision Centre keep on top of new studies, like two large-scale trials that will be published soon. "We tell people that [the studies] will provide better quality evidence, so that may modify their decisions based on the new evidence," says O'Connor.

The decision-support algorithm informs the physician and patient about the therapy's risks and benefits, clarifies the importance of these risks and benefits and offers practical strategies to involve patients in decision-making and follow-up.

"The kit reduces uncertainty," says O'Connor. "Patients feel happier with the decision they've reached. They feel more supported and are clearer about what's important to them in the decision, clearer about their values."

The algorithm has been so successful that O'Connor is working with other groups that are developing similar kits, including members of the McMaster Decision Board Group and ICES. She hopes to distribute the HRT kit through physicians' offices and pharmacies in the hope the take-home kit will be loaned to patients.

## Development of decision aid a team effort

Members of the Hormone Replacement Therapy Decision Aid Group are:

Dr. **Annette O'Connor**, associate professor, University of Ottawa (U of O); senior investigator, Ottawa Civic Hospital Loeb Research Institute (OCHLRI);

Dr. **Peter Tugwell**, professor, U of O Faculty; chair, Department of Medicine, Ottawa General Hospital;

Dr. **Tom Elmslie**, associate professor, U of O; director, Clinical Epidemiology Unit, Sisters of Charity Hospital of Ottawa; scientific consultant, *CMAJ*;

Dr. **George Wells**, associate professor, U of O Faculty of Medicine; associate director, OCHLRI Clinical Epidemiology Unit;

Dr. **Elaine Jolly**, associate professor, U of O; director, Reproductive Endocrinology Clinic, Ottawa General Hospital;

Dr. **Ruth McPherson**, associate professor, U of O and McGill University; director, Lipid Clinic and Lipid Research Laboratory, U of O Heart Institute;

Dr. **Ian Graham**, postdoctoral fellow, OCHLRI Clinical Epidemiology Unit;

Dr. **Helen Bunn**, professor, U of O Faculty of Health Sciences;

Dr. **Gary Hollingworth**, assistant professor, U of O Faculty of Medicine; research coordinator, Family Medicine Centre, Sisters of Charity Hospital;

Dr. **Andreas Laupacis**, professor, U of O Faculty of Medicine; director, OCHLRI Clinical Epidemiology Unit; and

**Elizabeth Drake**, program coordinator, Ottawa Health Decision Centre, OCHLRI Clinical Epidemiology Unit.