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FALL EDITORIAL

The Future of Nursing Research Journals: Resisting the "Pabulum" Format

The keynote address at this year's international conference for editors of nursing journals was delivered by a former nurse, Linda J. Shinn, who is now Principal of the Consensus Management Group, a marketing company in Washington, DC. The focus of her address was the future of nursing journals and the conditions that might ensure their survival into the next millennium. Shinn told her audience that journals tailored to their readership, with a presentation that relies on visuals and "short bytes" rather than on lengthy text, will have a better chance of surviving.

This was not the first time I had heard such a message. Many people believe that in these times information must be presented in an entertaining and appealing way, or delivered as "pabulum" — that is, in a pre-digested, bulleted form. The argument rests on the belief that Information Age readers are accustomed to receiving their information in this form exclusively. One could argue, however, that although such an approach may be appropriate for some nursing journals, it should not become the model. If scholarly nursing journals were to opt for the pabulum format, nursing as a profession, and ultimately our status as a discipline, might be seriously compromised.

A discipline's knowledge is dependent on the originality and quality of the research it publishes. Clinicians and scholars must have access to detailed research reports, rather than just précis versions, if they are to assess the validity, applicability, and implications of findings. Moreover, a summary approach will not facilitate the publication of complex studies. The authors of complex studies will have to simplify and, in the process, select and exclude details. Great advances in knowledge have been stimulated by serendipitous, secondary findings. What is insignificant and of little interest to one researcher may be significant and of great interest to another.

A second major concern is that we will be active participants in a lowering of standards and will fail to attract scholars and clinicians who know how to think. A scholar is created when an investigator has to

struggle with an idea, grapple with an issue, identify nuances, and critically evaluate what is strong and what is weak in a research study. Simplified presentation of information does not foster the development of critical thinking skills.

If nursing journals choose to adopt the pabulum format, the hard-won reputation of nursing as a serious scientific discipline will be badly damaged. Who is going to take our research seriously if its findings are presented in bytes? What image will we be projecting if our scholarly articles consist of pictures and catchy phrases? Many of our own scholars will, as they did in the past, turn to more serious, respected journals in other disciplines to publish their studies; thus their work will be less accessible and less visible to nurses.

We must keep in mind that although pabulum is easily digested, it is not tasty or satisfying. If nursing journals accept such a prescription for survival, they might make it into the next millennium, but nursing as a respected, scholarly discipline and profession surely will not.

Laurie N. Gottlieb
Editor

ÉDITORIAL D'AUTOMNE

L'avenir des revues de recherche en sciences infirmières : Une résistance au format synthétique

Le discours-programme prononcé à la conférence internationale des rédacteurs de revues en sciences infirmières a été livré, cette année, par une ancienne infirmière, Linda J. Shinn, qui est maintenant cadre de direction au Consensus Management Group, une entreprise de marketing de Washington, D.C. Ce discours traitait de l'avenir des revues en sciences infirmières et des conditions qui pourraient assurer leur entrée dans le prochain millénaire. Selon M^{me} Shinn, les revues dont le contenu répond aux goûts de leur lectorat et qui comportent une présentation fondée sur des éléments visuels et un style littéraire « format-éclair » auront des possibilités de survie supérieures.

Ce n'était pas la première fois que j'entendais de tels propos. Plusieurs sont d'avis que de nos jours, l'information doit être présentée de manière divertissante et attrayante, ou livrée en format synthétique — c'est-à-dire une information-éclair pré-digérée. L'argument s'appuie sur une croyance selon laquelle les lecteurs de l'Âge de l'Information ont l'habitude de recevoir les données uniquement sous cette forme. Toutefois, on pourrait soutenir que même si cette approche s'avère appropriée pour certaines revues en sciences infirmières, elle ne devrait pas constituer pour autant un modèle. Si les revues de recherche en sciences infirmières publiées par les universités optaient pour le format synthétique, l'exercice des soins infirmiers en tant que profession et ultimement notre statut en tant que discipline reconnue pourraient être sérieusement menacés.

La connaissance qui relève d'une discipline dépend de l'originalité et de la qualité des recherches publiées dans ce domaine. Les cliniciens et les chercheurs doivent avoir accès à des rapports de recherche détaillés plutôt que des écrits sous forme contractée s'ils veulent accéder aux données de validation et d'application ainsi qu'aux implications qui découlent des résultats. De plus, une approche fondée sur le résumé ne favorisera pas la publication d'études complexes. Les auteurs de telles études devront simplifier et, par conséquent, sélectionner et exclure certains détails. De grands pas en matière de connaissance ont été réalisés

à partir de résultats qui étaient de nature secondaire et inattendue. Ce qui est sans intérêt pour un chercheur peut s'avérer de grande importance pour un autre.

Une autre préoccupation majeure est le fait que nous participerions activement à l'appauvrissement de la qualité, ce qui provoquerait un désintéressement de la part des chercheurs universitaires et des cliniciens qui excellent dans le processus de la pensée. Un chercheur devient un érudit lorsqu'il travaille ardemment à explorer une idée, qu'il s'attaque à une question, qu'il identifie les nuances et qu'il relève, de manière critique, les forces et les faiblesses d'une recherche. La présentation de l'information de manière simplifiée ne favorise pas le développement de la pensée critique.

Si les revues du domaine choisissent d'adopter le format synthétique, la reconnaissance difficilement acquise des sciences infirmières en tant que véritable discipline scientifique sera gravement atteinte. Qui accordera une crédibilité à nos recherches si les résultats sont présentés en format-éclair? Qu'afficherons-nous comme image si nos articles de recherche se limitent à des illustrations accompagnées de quelques phrases accrocheuses? Plusieurs de nos propres chercheurs se tourneront, comme ils l'ont fait dans le passé, vers des revues plus sérieuses et crédibles d'autres disciplines pour publier leurs études. Par conséquent, le personnel infirmier aura moins accès à leurs travaux, lesquels seront moins visibles.

Nous devons nous rappeler que même si le format synthétique est facilement assimilable, il n'est pas pour autant nourrissant et satisfaisant. Si les revues en sciences infirmières acceptent une telle prescription pour assurer leur survie, elles atteindront peut-être le prochain millénaire mais les sciences infirmières, en tant que discipline de recherche et profession crédibles, n'en fera pas autant.

Laurie N. Gottlieb
Rédactrice

Focus: *Values and Decision Making*

GUEST EDITORIAL AND DISCOURSE

Consumer/Patient Decision Support in the New Millennium: Where Should Our Research Take Us?

Annette M. O'Connor

[W]hile Canada has a lot of health-related information, much of this information is neither accessible nor usable.... How can we develop methods and incentives which encourage providers, administrators, and policy makers to adopt best evidence into practices, programs and policies to support decisions related to... health care... what can be put in place to make it easier for the public to become more involved in the decision making process surrounding... health care and their personal health?

– National Forum on Health Key Strategic Direction:
Using Better Evidence for Better Decisions

The focus of this *CJNR* issue on decision making and values reflects the growing interest in the area of decision making and highlights the contributions nurses have made to the science of decision support for patients. Lesley Degner and Hilary Llewellyn-Thomas have devoted their research careers to the systematic development and evaluation of clinical tools to assess patients' preferences for decision participation and for treatment alternatives. The careful evolution of their work stands as a model for nascent researchers who wish to contribute to the development of constructs, measures, and clinical decision-support tools. Although the influence of Drs. Degner and Llewellyn-Thomas extends beyond Canada's borders and the nursing discipline, I am truly delighted that a summary of their work has found a home in our national nursing research journal.

Several factors have contributed to the interest we are witnessing in decision support for patients. The rise of consumerism and patient empowerment has shifted the emphasis from the more passive informed consent to informed choice. Health-services research in practice variations and the movement for "evidence based" practice have stimulated the dissemination of clinical guidelines not only to practitioners but also to patients, particularly when the best course of treatment is uncertain; when the decision involves making value trade-offs among risks and benefits; or when patients can play a role in reducing inappropriate use of health services. The increase in technology assessments of current interventions using decision analysis has led to increased identification of treatment decisions that are "utility" or "value" sensitive — that is, dependent on the importance that patients place on the risks relative to the benefits. Large outcomes studies and overviews have provided stable estimates of benefits and risks among patient subgroups, which permits tailoring of decision aids. There is also considerable interest in the cost-effectiveness of adopting a more selective, patient preference-oriented approach and reserving interventions for those patients who consider the treatment benefits to outweigh the risks (for example, reserving palliative surgery for those patients who consider alleviation of their symptoms to be worth the surgical risks, rather than basing a surgical policy on the utilities of the average patient).

The role of practitioners in helping patients make decisions varies according to the nature of the decisions, the preferences for control in decision making, and the expertise of clinicians and patients. Several practice guidelines advocate a shared decision-making approach, and Marilyn Rothert of the Faculty of Nursing at Michigan State University has described the corresponding roles as follows: Practitioners provide information about the options available, the risks and benefits, and the health-care resources that are required and available; patients convey their value for the risks and benefits and the personal, financial, and instrumental resources that are available to help them make and implement the decision. Both Degner and Llewellyn-Thomas have contributed tools to facilitate this process.

Degner's tool helps us assess the role that patients want to play in decision making so that we can tailor our support to their needs. Her work raises as many questions as it answers. How do preferences vary among cultural groups? Which decisions are associated with stronger preferences for decision participation and which decisions are associated with weaker ones? How do preferences change over time? Should we tailor our counselling to decision participation preferences or should we

try to change them? If the former approach is advocated, which strategies work best with patients who have different participation profiles?

Llewellyn-Thomas has developed a strategy for helping patients to consider and communicate their values. How does this strategy improve the quality of patient-practitioner communication, the quality of the decision, and the outcomes of the decision? Are patients more likely, if this strategy is used, to choose alternatives consistent with their personal values? Will they be more satisfied with their decisions and more likely to stay with their decisions? What is the efficacy of this approach to values clarification relative to other approaches?

The annotated bibliography on decision-support interventions published in this issue of *CJNR* highlights the early phase of development for this field of inquiry. Why only the early phase, when patient-education research has existed for well over 30 years? Decision support can be distinguished from general patient education by virtue of its: focus on alternatives, benefits, and risks; tailoring of information to a patient's clinical risk profile; provision of detailed descriptions of the benefits and risks in functional terms; use of probabilities, when these are available, to describe the likelihood of benefits and risks; asking patients to consider their values either implicitly or explicitly during deliberation; and emphasis on choice and shared decision making. Decision support evolved from the general field of patient education through a fusion, in the late 1980s and the 1990s, of consumer and health-services research influences.

To date, most decision-support applications have been developed for patients with chronic or life-threatening diseases, particularly cancer. The focus has been on decisions about surgical or medical therapies, although a few studies have considered preventive, early-detection, end-of-life, and clinical-trial participation issues. The decisions are characterized by the need for careful deliberation about alternatives due to the risk or uncertainty of the outcomes or the value-laden nature of the decision where benefits need to be balanced against risks.

The approaches used to provide decision support vary widely, from personal counselling to the use of structured aids as adjuncts to counselling. Some include formal decision analytic methods in which the patient's utilities are elicited and incorporated into a decision tree. Others use a decision analytic perspective to structure the aid, but rely on the patient's intuitive choice, rather than a mathematical combination of probabilities and utilities, to guide action. Research over the past 15 years has demonstrated the poor correspondence between intuitive choices and those derived from expected-utility decision analysis.

Advocates of the intuitive-choice approach maintain that decision analysis should not be used in prescribing choice because it is poor in describing actual decision behaviour. Proponents of decision analysis argue that individuals are incapable of processing complex information and therefore should be guided by logical mathematical models. This debate will probably continue as both approaches are applied and evaluated in clinical practice.

The decision aids vary in the ways in which the probability of benefits and risks are described (numerical, non-numerical) and illustrated (pie charts, bar charts, 100 figures). The approach to values clarification also varies (implicit, or explicit using tradeoff tasks, relevance charts, weigh scales, or utility assessments). The provision of normative information describing the opinions of experts and patients also differs. The impact of these variations on actual decisions has yet to be established.

The decision aids vary widely in mode and cost of delivery. They are presented via decision boards, interactive video discs, personal computers, audiotapes, booklets, pamphlets, and group presentations. Their relative effectiveness, efficiency, and acceptability need to be evaluated.

The published studies evaluating decision aids are few in number and often have several methodological limitations. For example, only 14 of the 31 published studies used a randomized trial design and only five of these had a usual-care control arm. Even in these five studies, it was not always clear what the decision was and whether all patients were actively considering the decision. Moreover, most of the studies were limited in generalizability because of the small and non-random sampling. Therefore it is difficult to make any conclusive statements regarding the efficacy of decision support relative to usual care for a broad range of patients facing actual decisions.

Despite these limitations, the following trends have been noted. Decision-support strategies have received generally consistent positive ratings by patients in terms of feasibility, acceptability, length, balance, clarity, amount of information, and usefulness in decision making. Yet to be determined is the generalizability of these results to different groups who vary by age, education, ethnicity, and preferences for control in decision making and the comparative advantage of different approaches. Utilization of decision aids in general-education programs such as CHES is fairly limited, because many users are not actually at that point in decision making.

Before/after studies have found that decision aids usually increase patients' general knowledge of alternatives, risks, and benefits after

they are administered. However, there do not appear to be any gains in general knowledge when information about alternatives, benefits, and risks is presented via different delivery methods (e.g., video, brochure/pamphlet, group, audiotape, computer) or intensities of decision support. The lack of difference is presumably due to the considerable overlap in content provided in the different interventions.

Tailored decision aids have the potential to create realistic expectations (due to the tailored probabilistic information) and to clarify values (due to detailed information about outcomes from which value judgments can be formed and the explicit values-clarification exercises). There have been few studies to examine impact on expectations. In terms of clarifying values, three studies have shown that decision aids promote value congruence with decisions. More investigation is needed using these important endpoints, which tap two key differences between decision-aid interventions and usual-care approaches.

Both before/after and comparative studies have found the impact of decision aids on decisions to be quite variable. This variability may be the result of the nature of the decision, the strength of the baseline predispositions toward the issue, the degree to which the decision was hypothetical, or methodological limitations. Four of the five stronger randomized trials with patients at the point of decision making found no differences in decisions. The one exception was a study comparing information presentations on prostate screening (single sentence versus detailed information on benefits and risks). This is an area that clearly needs more investigation. Optimal study designs should have baseline predispositions, be randomized, have a control group, clearly define the decision, and recruit patients at the point of decision making.

Even less is known about the impact of decision aids on patients' satisfaction with the decision and with decision support. Practitioners' reactions to using decision aids are under-explored. Evaluations are also needed to determine the impact on long-term decision persistence, health outcomes, health-care utilization, and costs.

In conclusion, the National Forum on Health has challenged us to find ways of involving consumers/patients in decisions about their personal health. Many tools and approaches have been developed to assist us in helping our clients make difficult decisions. However, the jury is still out regarding their effectiveness, efficiency, and suitability with different groups under different circumstances. We have our work cut out for us until well past the year 2000!

Annette M. O'Connor, R.N., Ph.D., is Professor and Ontario Ministry of Health Career Scientist, University of Ottawa School of Nursing.

Le point : Les valeurs et la prise de décision

ÉDITORIAL ET DISCOURS INVITÉS

À l'âge du nouveau millénaire, le soutien à la décision auprès du consommateur/patient : Où nos recherches nous mènent-elles ?

Annette M. O'Connor

[A]lors que le Canada possède beaucoup d'information sur la question de la santé, une grande part de celle-ci n'est pas accessible ou utilisable... Comment pouvons-nous développer des méthodes et des mesures incitatives qui amèneront les fournisseurs de services, les administrateurs et les décideurs à adopter les meilleurs résultats de recherche et les convertir en pratiques, en programmes et en politiques dans le but d'appuyer des décisions en matière de ... santé... que pouvons-nous mettre en place pour favoriser une plus grande participation de la population au processus décisionnel concernant les soins de santé et la santé des individus ?

– Forum national sur la direction stratégique clé en matière de santé :
utiliser de meilleures données pour prendre de meilleures décisions

Le thème de ce numéro de la RCRSI, la prise de décision et les valeurs, illustre l'intérêt croissant en matière de processus décisionnel et met en lumière les contributions du personnel infirmier à la science du soutien au patient en situation décisionnelle. Lesley Degner et Hilary Llewellyn-Thomas ont consacré leur carrière à étudier la question du développement systématique et de l'évaluation des outils cliniques utilisés pour identifier les préférences des patients en ce qui a trait à la participation aux décisions et aux choix de traitements. Leurs travaux, de par leur évolution méticuleuse, servent de modèle pour les nouveaux chercheurs désireux de contribuer au développement de concepts, de

normes et d'outils de soutien pour la prise de décisions cliniques. Même si l'influence de Degner, Ph.D., et Llewellyn-Thomas, Ph.D. s'étend au-delà des frontières du Canada et des sciences infirmières, j'ai l'immense plaisir de voir, dans les pages de notre revue nationale de recherche en sciences infirmières, un résumé de leurs travaux.

Plusieurs facteurs ont contribué à créer un intérêt, dont nous sommes témoins, à la question du soutien à la décision auprès du patient. La hausse du consommateurisme et de la notion de pouvoir chez le patient a transformé les rapports. Du consentement éclairé et passif, nous sommes passés au choix éclairé. Les recherches sur les variations de pratiques en santé et le mouvement pour une « pratique fondée sur des preuves » ont stimulé la diffusion des principes directeurs des activités cliniques, non seulement auprès des praticiens mais aussi auprès des patients, surtout dans les situations suivantes : lorsque nous ne sommes pas certains du choix de la meilleure démarche thérapeutique à suivre ; lorsque la décision implique un choix de gains et de pertes ; ou lorsque les patients peuvent jouer un rôle dans la réduction d'une utilisation inappropriée des services de santé. Une hausse des évaluations technologiques des interventions actuelles, lesquelles s'appuient sur l'utilisation de l'analyse de décision, nous a mené à identifier de plus en plus les décisions de traitement qui sont axées sur les notions de « préférences » ou de « valeurs » — notamment qui dépendent de l'importance qu'accordent les patients aux risques liés aux avantages. D'importantes études et documents de résumé traitant des résultats ont fourni des estimations stables en ce qui a trait aux avantages et aux risques parmi des sous-groupes de patients, ce qui permet d'adapter les outils d'aide à la décision. De plus, on s'intéresse beaucoup à la rentabilité d'une approche davantage sélective et axée sur les préférences des patients, où l'on réserve les interventions aux patients pour qui les avantages du traitement excèdent les risques (par exemple, réserver la chirurgie palliative aux patients qui considèrent que le soulagement de leurs symptômes dépassent les risques liés à la chirurgie, plutôt que de fonder une politique en matière de chirurgie sur les préférences du patient moyen).

Le rôle des praticiens en tant que personnes ressources aidant les patients à prendre des décisions varie selon la nature des décisions, les préférences en matière de contrôle dans la prise de décision et les compétences des cliniciens et des patients. Plusieurs directives de la pratique préconisent une approche de partage dans la prise de décision, et Marilyn Rothert de la Faculté des Sciences infirmières de la Michigan State University donnait la description suivante des rôles correspondants : les praticiens fournissent de l'information concernant les options

offertes, les risques et les avantages, ainsi que les ressources requises et offertes en matière de soins de santé; les patients font part de leurs choix en ce qui a trait aux risques et avantages, ainsi que de leurs ressources personnelles, financières et instrumentales qui sont à leur portée et qui les aident à prendre une décision et à la mener à terme. Degner et Llewellyn-Thomas ont toutes les deux contribué à mettre au point des outils qui facilitent ce processus.

L'outil de Degner nous aident à évaluer le rôle que les patients désirent jouer dans la prise de décision, ce qui nous permet d'adapter notre soutien à leurs besoins. Ses travaux soulèvent autant de questions qu'ils n'en répondent. Quelle est la variation des préférences parmi les groupes culturels? Quelles sont les décisions qui sont associées à une préférence plus marquée pour la participation à la prise de décision, et quelles sont les décisions qui sont associées à une préférence moindre? Comment les préférences se transforment-elles au cours du temps? Devons-nous adapter nos interventions d'aide aux préférences de participation à une décision ou devons-nous tenter de changer ces préférences? Si la dernière approche est préconisée, quelles sont les stratégies les plus efficaces auprès des patients qui présentent des profils de participation différents?

Llewellyn-Thomas a élaboré une stratégie qui aide les patients à prendre contact avec leurs valeurs et à les communiquer. Comment cette stratégie améliore-t-elle la qualité de la communication patient-praticien, la qualité des décisions prises et l'aboutissement du processus décisionnel? Si cette stratégie est utilisée, les patients sont-ils plus enclins à effectuer des choix qui correspondent à leurs valeurs personnelles? Seront-ils plus satisfaits face à leurs décisions et auront-ils plus tendance à adhérer à leurs choix? Quelle est l'efficacité relative de cette approche à la clarification des valeurs en comparaison avec d'autres approches?

La bibliographie commentée sur les interventions d'aide à la décision publiée dans ce numéro de la RCRSI met en lumière le fait que ce domaine de recherche n'est qu'à un stade préliminaire. Pourquoi n'est-il qu'à ses débuts, alors que la recherche traitant de l'éducation des patients existe depuis plus de 30 ans? Les facteurs suivants distinguent le soutien à la décision de l'éducation des patients en général: l'accent sur les solutions de remplacement, les avantages et les risques; l'adaptation de l'information au profil clinique de risques d'un patient; la communication de descriptions détaillées des avantages et des risques en termes fonctionnels; l'utilisation des probabilités, lorsque celles-ci sont disponibles, pour décrire la vraisemblance des avantages et des

risques ; une intervention qui invite le patient à se pencher sur ses valeurs, de manière implicite ou explicite, au cours du processus de délibération ; et un accent sur le choix et la prise de décision conjointe. Le soutien à la décision est un procédé issu du domaine de l'éducation des patients, qui est né d'une fusion d'influences relevant des services aux consommateurs et des services de santé de la fin des années 80 et des années 90.

Jusqu'à maintenant, la plus grande part des applications de soutien à la décision ont été développées pour des patients souffrant de maladies chroniques ou graves, notamment le cancer. L'accent a été mis sur les décisions qui ont rapport aux thérapies chirurgicales ou médicales. Toutefois, quelques recherches ont été menées sur des sujets touchant la participation à la prévention, le dépistage précoce, l'étape de fin de vie et les essais cliniques. Les décisions sont caractérisées par le besoin d'une délibération méticuleuse concernant les solutions de remplacement, pour cause de risques ou de résultats incertains, ou à cause de la nature chargée d'une décision, sur le plan des valeurs, dans des circonstances où les avantages doivent être mesurés aux risques.

L'approche utilisée pour fournir un soutien à la décision varie grandement, soit du counseling individuel à des outils d'aide structurels qui constituent un appoint au counseling. Quelques-uns de ces outils incluent des méthodes officielles d'analyse de décision, où le patient est invité à faire part de ses préférences, lesquelles sont intégrées à un arbre de décision. D'autres utilisent une perspective analytique des décisions pour structurer l'aide et orientent leur action en fonction des choix intuitifs du patient plutôt que de se fonder sur une combinaison mathématique de probabilités et de préférences. Les recherches menées au cours des 15 dernières années ont démontré que les choix intuitifs correspondent peu aux choix fondés sur l'analyse de décision, qui s'appuie sur des préférences prévues. Les précurseurs de l'approche du choix intuitif soutiennent que l'analyse de décision ne devrait pas être utilisée dans la prescription de choix parce qu'elle décrit mal le comportement décisionnel réel. Les avocats de l'analyse de décision argumentent que les individus sont incapables de recevoir et d'assimiler des données complexes et par conséquent, ceux-ci devraient être guidés dans leur décision à l'aide de modèles mathématiques logiques. Ce débat se poursuivra sans doute puisque les deux approches sont appliquées et évaluées dans la pratique clinique.

Les outils d'aide à la décision se distinguent dans leurs descriptions des probabilités des avantages et des risques (numérique, non-numérique) et dans les illustrations utilisées (diagrammes à secteurs,

diagrammes à barres, graphiques à banderolle). L'approche à la clarification des valeurs est aussi différentes (implicite ou explicite, avec l'utilisation d'exercices de rentabilité, de tableaux de pertinence, d'échelles de mesure ou d'évaluations des préférences). Il y a aussi des différences en ce qui a trait à la communication d'information normative décrivant les opinions des experts et des patients. Les effets de ces variations sur les décisions réelles restent à déterminer.

Les outils d'aide à la décision varient grandement en ce qui a trait au mode et aux coûts d'administration. Ils sont présentés au moyen de conseils de décision, de vidéodisques interactifs, d'ordinateurs personnels, de cassettes audio, de brochures, de dépliants et d'ateliers. Leur efficacité, efficience et acceptabilité doivent faire l'objet d'une évaluation.

Les études publiées qui évaluent les outils d'aide à la décision sont peu nombreuses et comportent souvent plusieurs limites méthodologiques. Par exemple, parmi les 31 études publiées, seulement 14 d'entre elles ont utilisé un modèle avec essais sur échantillons pris au hasard. De plus, seulement cinq d'entre elles comportaient un groupe de contrôle recevant des soins usuels. Même dans ces cinq études, il était parfois difficile de saisir qu'elle était la nature de la décision et d'identifier si tous les patients avaient effectué une démarche d'étude active de cette décision. De surcroît, la plupart des études ne permettaient pas de tirer des conclusions générales, en raison de leur échantillonnage limité et sélectif. Par conséquent, il est difficile de statuer sur l'efficacité du soutien à la décision, en relation aux soins usuels, auprès de patients qui ont à prendre de vraies décisions.

Malgré ces limites, les tendances suivantes ont été relevées. Les stratégies de soutien à la décision ont généralement été évaluées de manière positive par les patients quant à leur faisabilité, leur acceptabilité, leur durée, leur équilibre, leur clarté, la quantité d'information donnée et leur utilité dans le processus de prise de décision. Ce qui reste encore à établir, c'est la possibilité d'appliquer ces résultats de manière générale à des groupes de patients diversifiés au niveau de l'âge, de la scolarité, de l'origine culturelle et des préférences en matière de contrôle de la prise de décision. Il conviendrait également d'examiner les avantages comparatifs des différentes approches. L'utilisation d'outils d'aide à la décision dans les programmes d'éducation générale, tels que CHESS, est plutôt restreinte parce que plusieurs usagers ne sont pas encore rendus à cette étape du processus décisionnel.

Les études avant-après ont démontré que, une fois qu'ils sont appliqués, les outils d'aide à la décision permettent habituellement aux

patients d'augmenter leur connaissance générale des solutions de remplacement, des risques et des avantages. Cependant, il ne semble pas y avoir de gains supplémentaires dans le niveau de connaissance général du patient lorsque l'information sur les solutions de remplacement, les risques et les avantages est présentée au moyen de différents modes de transmission (p. ex. support audio, vidéo ou informatique; brochure, dépliant, ateliers, etc.) ou lorsque le soutien à la décision varie en intensité. Ceci est vraisemblablement dû à un important chevauchement de l'information donnée lors de chacune des interventions.

Les outils adaptés d'aide à la décision ont le potentiel de créer des attentes réalistes (en raison de l'information probabiliste adaptée) et de clarifier les valeurs (grâce à l'information détaillée à propos de résultats pouvant mener à la formation de jugements de valeurs et aux exercices de clarification des valeurs). Peu d'études, jusqu'à présent, se sont attardées à l'impact de ces outils sur les attentes des patients. En ce qui concerne la clarification des valeurs, trois études ont démontré que les outils d'aide à la décision mettent de l'avant l'adéquation entre les décisions et les valeurs du patient. Il faudra approfondir ces deux constats importants, qui indiquent deux différences clés entre les interventions d'aide à la décision et les approches de soins usuels.

Des études avant-après ainsi que des études comparatives ont conclu que les effets de l'aide à la décision sur les décisions mêmes sont très variés. Cette variance résulte possiblement de la nature de la décision, la force des prédispositions de base face à la question, le degré de l'aspect hypothétique de la décision ou les limites de la méthodologie. Aucune différence n'a été notée dans les décisions, dans le cadre de quatre des cinq essais plus complets choisis au hasard et menés auprès de patients qui sont sur le point de prendre une décision. La seule exception relevée était une étude comparative de présentations d'information sur le dépistage du cancer de la prostate (une phrase unique par opposition à une information détaillée sur les avantages et les risques). Cet aspect requiert assurément un examen plus poussé. Les méthodologies optimales doivent comporter des prédispositions de base, utiliser un échantillonnage pris au hasard, comporter un groupe de contrôle, définir clairement la décision et recruter les patients qui sont sur le point de prendre une décision.

Nous connaissons encore moins les effets des outils d'aide à la décision sur le degré de satisfaction du patient face à la décision prise et au soutien à la décision. Les réactions des praticiens concernant l'utilisation de l'aide à la décision a été très peu recensée. Il y a aussi un besoin de déterminer quels sont les effets en matière de maintien d'une déci-

sion à long terme, les résultats sur la santé, l'utilisation de soins de santé et les coûts.

Pour conclure, le Forum national sur la santé nous a mis à défi de trouver des façons qui favoriseraient la participation des consommateurs/patients aux décisions liées à leur santé. Plusieurs outils et approches ont été développés pour nous aider à assister les patients dans une prise de décision difficile. Toutefois, le juré délibère toujours sur leur efficacité, leur efficience et leur convenance en ce qui a trait à leur utilisation auprès de différents groupes, dans différentes circonstances. Un travail de taille qui nous mènera bien au-delà l'an 2000!

Annette M. O'Connor, i.a., Ph.D., est professeure à l'École des Sciences infirmières de l'Université d'Ottawa, et investigatrice scientifique au ministère de la Santé de l'Ontario.

The Control Preferences Scale

**Lesley F. Degner, Jeff A. Sloan,
and Peri Venkatesh**

L'échelle d'identification des préférences (ÉIP) a été créée dans le but d'évaluer un concept issu d'une théorie empirique sur la manière dont les décisions de traitement sont prises chez les personnes atteintes de maladies graves. Le concept d'identification des préférences est défini comme étant «le degré de contrôle qu'un individu désire exercer en ce qui a trait aux décisions prises concernant le traitement médical». L'ÉIP fait usage de cinq fiches qui illustrent différents rôles dans la prise de décision de traitement. Ces fiches contiennent un énoncé ainsi qu'un dessin humoristique, et les rôles présentés couvrent une gamme de scénarios, allant d'une décision de traitement prise uniquement par la personne jusqu'à une décision prise uniquement par le médecin, en passant par un scénario où la décision est prise conjointement par le patient et le médecin. En utilisant l'ÉIP, les sujets effectuent une série de comparaisons par paires dans le but d'établir l'ultime degré de préférence face aux cinq fiches. Ces degrés sont analysés à l'aide de la théorie du dépliage afin de déterminer la distribution des préférences auprès de différentes populations et l'effet des covariables sur les préférences des consommateurs. L'échelle a été testée chez de populations variées, lesquelles couvraient un bassin allant du public général à des groupes extrêmement stressés. L'ÉIP s'est avérée être une mesure de préférence de rôles qui est cliniquement pertinente, d'application facile, valable et fiable en ce qui a trait à la prise de décision en matière de soins de santé.

The Control Preferences Scale (CPS) was developed to measure a construct that emerged from a grounded theory of how treatment decisions are made among people with life-threatening illnesses. The control preferences construct is defined as "the degree of control an individual wants to assume when decisions are being made about medical treatment." The CPS consists of five cards that each portrays a different role in treatment decision-making using a statement and a cartoon. These roles range from the individual making the treatment decisions, through the individual making the decisions jointly with the physician, to the physician making the decisions. The CPS involves subjects in making a series of paired comparisons to provide their total preference order over the five cards. These preference orders are analyzed using unfolding theory to determine the distribution of preferences in different populations and the effect of covariates on consumer preferences. The scale has been tested in a variety of populations, ranging from the general public to highly stressed groups. The CPS has proven to be a clinically relevant, easily administered, valid, and reliable measure of preferred roles in health-care decision-making.

Interest in the consumer's potential role in health care has intensified as new perspectives emerge in medicine. The availability of treatment options with equivalent benefits in terms of survival have led to sug-

Lesley F. Degner, R.N., Ph.D., is Professor, Faculty of Nursing, University of Manitoba, Winnipeg. Jeff A. Sloan, Ph.D., is Lead Biostatistician, Mayo Clinic, Rochester, Minnesota. Peri Venkatesh, M.N., is Lecturer, Faculty of Nursing, University of Manitoba.

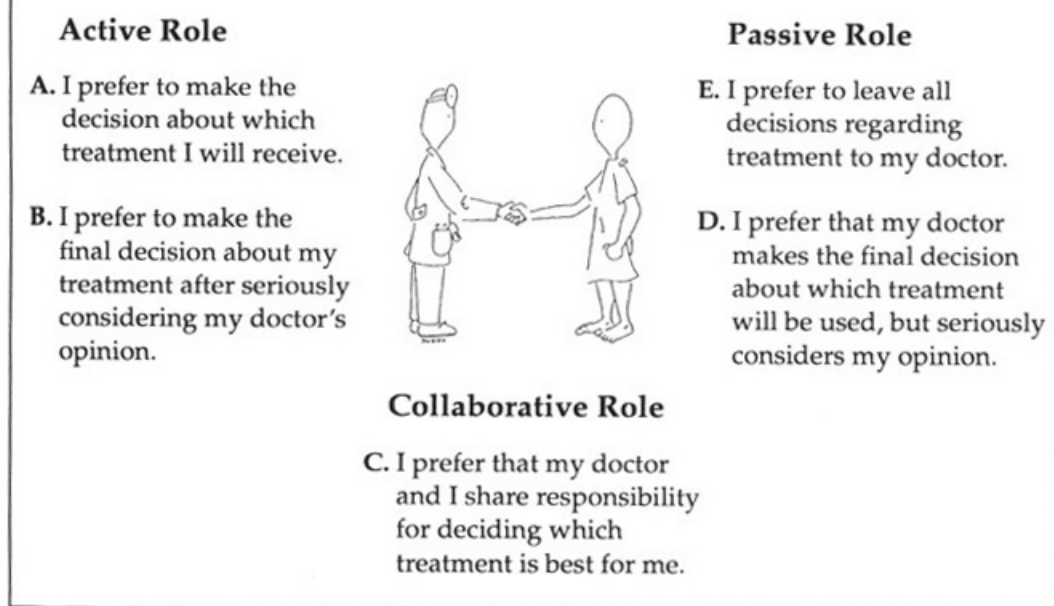
gestions that it should be the consumer's preferences that guide final selection of treatment (Ganz, 1992). Similarly, shrinking resources in health care have led to the realization that when patients select their own treatment they are likely to adopt a more conservative approach to treatment than would their physicians (Wennberg, 1990). Concern over the degree of control over treatment decisions that people are currently able to assume, as well as speculation about the degree of control they actually want, have intensified as a result of empirical evidence that individuals who exercise control over decisions regarding their medical treatment have better outcomes (Fallowfield, Hall, Maguire, & Baum, 1990; Greenfield, Kaplan, & Ware, 1985; Morris & Royle, 1988).

One of the greatest challenges facing investigators is how to measure the degree of control that consumers of health care actually want. This measurement objective has to be realized before variations in decisional preferences among members of different disease/treatment groups or users in different health-care settings can be described. Accurate measurement of consumer preferences also provides the basis for examining the relationship between assuming decisional control and health-care outcome (Wallston et al., 1991).

This paper will describe the development of the control preferences scale (CPS), a measure designed to elicit consumer preferences regarding participation in health-care decisions. The CPS consists of five cards portraying five different roles consumers could assume in treatment decision-making. Each role is described by a statement and a cartoon (see Figure 1). Subjects make paired comparisons of a series of subsets of two of the five cards to yield their total preference order for the roles, ranging from most to least preferred. These preference orders are analyzed using unfolding theory to yield estimates of the degree of control that different populations desire in the context of treatment decision-making.

This paper will describe the emergence of the control preferences construct and the development of the control preferences scale, as well as basic information about the underlying measurement model. Practical information on how to use the scale, including testing, scoring, and data analytic procedures, will be provided, so that investigators will be equipped to use the measure in a variety of health-care applications. The CPS is a clinically relevant, easily administered, valid, and reliable measure of preferred roles in health-care decision-making.

Figure 1 *The Control Preferences Card Set*



The cartoon is one of five that represent different roles in decision-making. This one represents the collaborative role.

Emergence of the Control Preferences Construct

The CPS has been two decades in development, beginning with a solid foundation in descriptive theory. The validity of the CPS derives from its grounding in the empirical world of health care. Between 1974 and 1978, data were collected in an extensive qualitative study designed to answer the general question "What happens when treatment decisions are made for patients with life-threatening illnesses?" (Degner & Beaton, 1987). The thesis of that study was that treatment decision-making took place within a social context, and as a result was influenced by that context, as opposed to being solely the product of the patient's medical condition and available treatments.

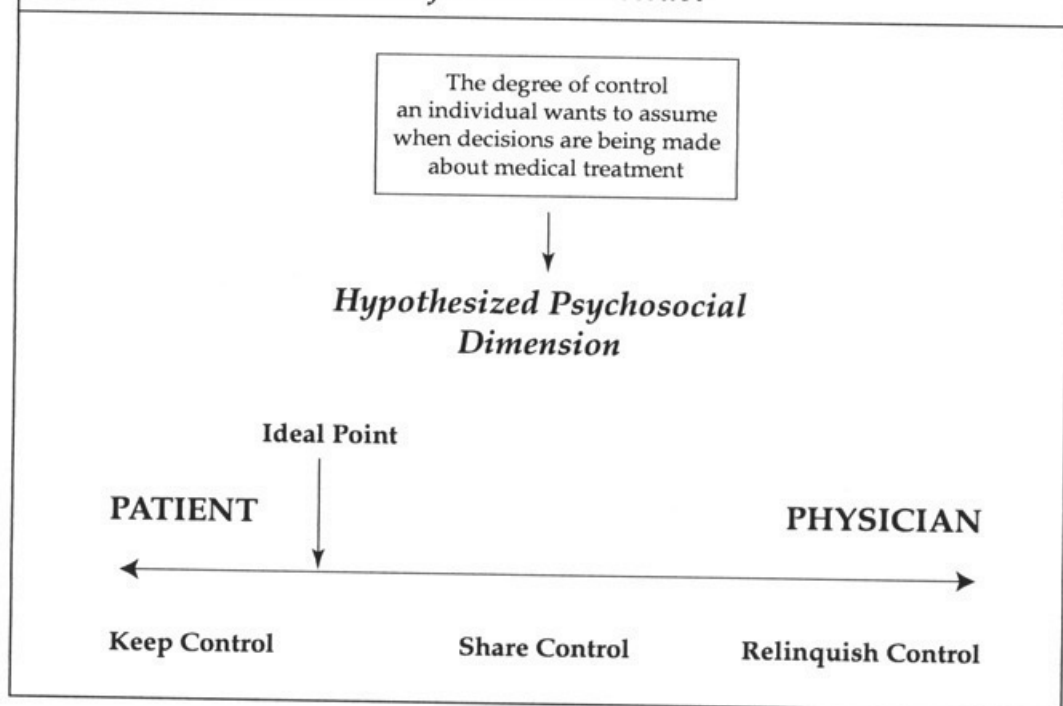
While several factors influenced the way in which treatment decisions were made, the central factor appeared to be "control over the design of treatment," or who actually selected the treatment that the patient received. Four patterns of decision-making were identified and described: provider-controlled, patient-controlled, family-controlled, and jointly controlled. This description (Degner & Beaton, 1987, pp. 27-37) provided the initial parameters for development of the control preferences construct. At the time that this study was conducted,

provider-controlled decision-making was dominant in health care, the other patterns being observed only rarely.

Description of the patterns of control led to the question "Do patients have preferences about the degree of control they actually want to exercise in treatment decision-making?" Informal participant observation at the University of Michigan Oncology Clinics and the Manitoba Cancer Treatment and Research Foundation Clinics during patients' first referral visits provided evidence for the existence of such preferences. Some patients refused to become involved in selecting their own treatment, even when urged to do so by the physician, essentially saying, "It's up to you, Doctor; you're the expert." Others indicated a need to discuss the available options with their physician, asking for the opportunity to go away and think about the discussion prior to making the final selection of treatment, with the physician, on the next visit. On rare occasions patients came obviously prepared, making it clear that it was their life and their body at stake and they would make their own treatment choices.

These observations led to formulation of the control preferences construct and the hypothesized psychological dimension that subsequently guided development of the measure (see Figure 2). The control preferences construct was defined as "the degree of control an individ-

Figure 2 *The Control Preferences Construct*



ual wants to assume when decisions are being made about medical treatment." Patients were hypothesized to have differing preferences about keeping control over treatment decision-making, sharing control with their physician, or relinquishing control to their physician. That is, the individual preference of any particular patient would fall at a particular point along that psychological continuum.

Distinction between Preference for Control and Preference for Information

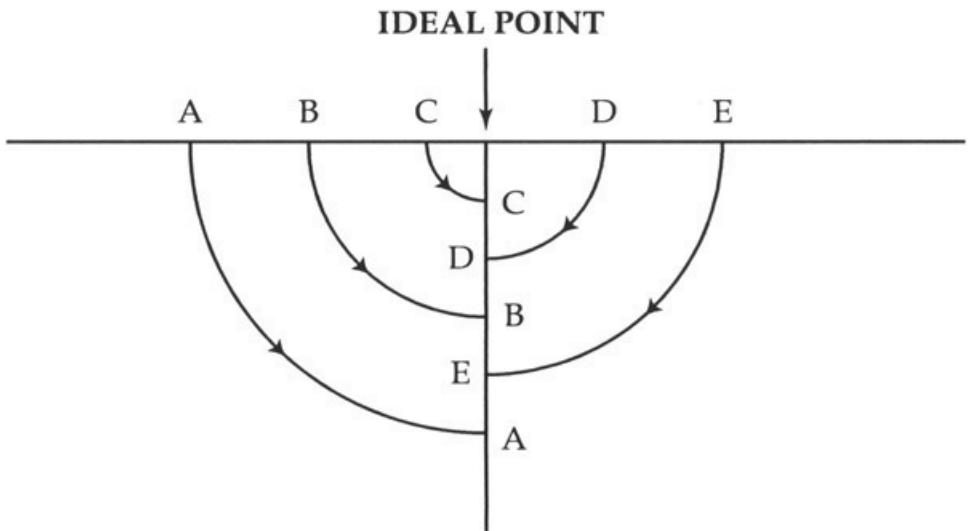
As described in the grounded theory of life-death decision-making that provided the basis for this work, desire for information is quite separate from degree of willingness to use this information in making choices (Degner & Beaton, 1987). Other authors have also emphasized the distinction between these constructs (Averill, 1973; Dennis, 1987; Krantz, Baum, & Wideman, 1980). As Sutherland, Llewellyn-Thomas, Lockwood, Trichler, and Till (1989) have noted, the need for information is probably related to the need to enhance psychological autonomy, and is not necessarily related to a desire to assume responsibility for treatment decisions. Put another way, people who want maximal information may have no interest in making choices about their medical care. The development of a separate measure of patients' priorities for information is described elsewhere (Bilodeau & Degner, 1996; Davison, Degner, & Morgan, 1995; Degner et al., 1997).

Development of the Control Preferences Scale

Selection of the Measurement Model

The hypothesis that patients have preferences about their level of control in treatment decision-making guided selection of the measurement model, which is referred to as unfolding theory (Coombs, 1976). Unfolding theory is based on the premise that an individual's preference corresponds to an ideal point on a continuum, and that this ideal point can be derived by presenting successive paired comparisons of stimuli that fall along the continuum. In the case of the CPS, the stimuli are the cards and the ideal point is represented by the order in which the subject places the cards, from most to least preferred (see Figure 1). Using Coombs's terms, this order is referred to as an individual, or I, scale. For example, the individual who wanted the greatest degree of control in decision-making would put the cards in Figure 1 in the order ABCDE, while the person who wanted the least control would put them in the order EDCBA.

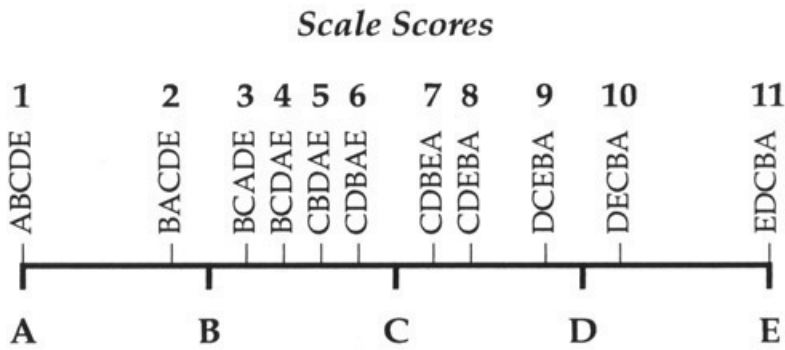
Figure 3 *Ideal Point CDBEA Obtained by Folding a J Scale (after Coombs)*



When series of I scales are unfolded, one can determine whether or not they are consistent with the existence of an underlying joint, or J, scale (see Figure 3). To offer a visual analogy, one can think of five beads (the stimuli or cards) fastened at different points on a string; the I scale is formed by picking up the string, or J scale, at some point (your ideal point) and folding it up. One then “unfolds” a whole series of these beaded strings (the preference orders) to determine whether the same J scale exists. When there are five stimuli (cards, in the case of the CPS), there are only 11 valid preference orders, or I scales, that would fall directly on the dimension (see Figure 4), out of a total possible 120 preference orders generated by every possible combination of five stimuli (cards). These valid preference orders are determined by the ordering of the stimuli (cards) and the midpoints between them (Coombs, 1976).

Unfolding analysis has proven to be a valid and reliable approach to instrument development, especially for unidimensional constructs (Bossuyt, 1990). This scaling approach is particularly useful in the measurement of abstract constructs. For example, Coombs applied unfolding theory to solve a problem his wife, a demographer, had met in measuring preferences for family size and composition among people in developing countries (Coombs, Coombs, & McClelland, 1975). The ease with which a measure based on unfolding theory could be applied in field settings, along with the opportunity for the first author to study with Dr. Coombs, provided the basis for selection of the measurement model.

Figure 4 Valid Permutations for the ABCDE Scale



Development of the Cards

The challenge for the investigator is to construct stimuli that fall on the hypothesized dimension, and that fall a “just noticeable difference” apart so that individuals can express their preferences while making minimal errors. The goal is to ensure that subjects can discriminate between adjacent stimuli. Construction of the stimuli for the CPS took place in two phases. In the first pilot test, five potential decisional roles were identified through participant observation and the participation of judges at the University of Michigan Oncology Clinics. For ease of administration of the measure, these roles were described in statements placed on five separate cards. The preliminary measure was then tested with a theoretical sample of 60 cancer patients, but one of the statements was found to be problematic and was subsequently dropped from the scale (Degner & Russell, 1988). This statement described the role in which the patient selected a physician who would administer the treatment that the patient had already selected. In retrospect, this role was identified because the statements were developed in an American clinic where patients assumed a very consumerist stance, while the pilot test was conducted in a Canadian clinic where patients tended to assume more passive roles in decision-making.

In the second phase, the statements were revised based on work by Strull, Lo, and Charles (1984) and pilot tested with 30 men who had testicular cancer. The second pilot test led to a revision of the statements and the addition of cartoons. Patients had difficulty understanding the concept of shared control; the addition of a cartoon helped them grasp this idea. Also, the literacy level of some patients was such that the research nurse had to read them the statements during testing; the cartoons provided these patients with a way to focus on the task.

Research Applications

Presentation Procedures

Administration of the CPS requires subjects to sort a series of cards through successive paired comparisons. The result of these comparisons consists of an ordered permutation of the letters that represent the five cards. In each of the three research procedures that have been developed and used to date, subjects are asked to consider one particular decision in expressing their preferences, such as their initial surgical treatment for breast cancer. Data obtained through administration of the CPS is meaningful only insofar as one particular decision of reference has been clearly identified.

1. Comparing every possible subset of two cards by hand: The first procedure is designed for use in cases in which the investigator has good control over the testing procedure and is committed to minimizing error. Such a case would be one in which the investigator has a single research assistant for whom extensive training can be offered, and in which a direct test of the hypothesis is essential. In addition, this procedure is restricted to clinical situations in which subject fatigue is not an issue.

This sorting procedure involves successive comparisons of all possible combinations of subsets of two of the five cards. The subject makes 10 paired comparisons [$n(n-1)/2$]. These pairs can be identified beforehand and arranged to obtain the maximal distance between the maximal number of items (Ross, 1974). The pairs are AB, BC, CD, DE, AC, BD, CE, AD, BE, and AE.

This method ensures that the subjects determine their rank ordering of preferences only after they have considered every possible combination of two cards. This approach minimizes measurement error, as evidenced by the results of a survey of 436 cancer patients: 63% fell directly on the hypothesized psychological dimension when this method was used.

2. Random-order presentation of the cards by hand: The second procedure is useful in instances where multiple data collectors with varying levels of education and ability might be employed, and in instances where a direct test of the hypothesis is less important. For example, the dimensionality of the construct in the population being tested might have been established in previous research.

The five cards are placed in random order through shuffling. The first two cards are placed in front of the subject, who is asked to

select the preferred card. The preferred card is placed on top of the non-preferred card. Then the next card is removed from the deck and placed beside the new stack of two cards. The subject is asked to compare the new card to the most preferred card. If the subject still prefers the previous card over the new one, the previous card is flipped over and the new card is compared to the next one in the new stack. If the subject prefers the new card, the new card is placed between the two cards in the new stack; if the previous second card is preferred, the new one is placed last in the new stack. This process continues until the subject's entire preference order is unfolded. The subject will make between five and 10 paired comparisons, depending on which card is drawn first, the order of the pack of cards, and the subject's ideal point. While easier to administer in the field, this approach leads to greater measurement error. For example, in a survey of the public, 53% of subjects fell directly on the hypothesized dimension (compared to the 63% of patients described above) (Degner & Sloan, 1992).

3. Fixed-order presentation of the cards by hand: The five cards are placed in the following fixed order: BDCEA. The procedure described in the above random-order presentation is used, beginning with the first two cards — B and D. Once the preferred card is selected, the next card (C) is compared to the preferred card, and so on, as described above. This procedure has proved to be very useful in clinical populations, since subjects can locate their ideal point in general terms (active, collaborative, passive) in their paired comparisons. A video has been developed to train research staff in this procedure.

Data Management

The back of each card is marked with a letter ranging from A to E. Immediately after the subject has completed the card sort, the preference order is recorded. For computer analysis, the data can be easily entered and manipulated as string variables. Subsequent variables are created as a result of whether the individual's preference order falls on the hypothetical metric, and ordinal variables are created to represent their particular location on the metric.

Data Analysis

Analysis of unfolding data comprises two phases: (1) confirming the metric's dimensionality, and (2) using scale scores to examine distribu-

tions and the impact of potential covariates. One of the datasets described in Degner and Sloan (1992) will be used to describe methods of data analysis. The exemplar dataset was collected from a consecutive sample of 436 newly diagnosed cancer patients who were tested in ambulatory oncology clinics. A total of 427 patients provided complete preference orders using the card-sort procedure described above. These preference orders provide the basis for the subsequent discussion and illustrations.

It is important for the investigator to verify that subjects actually use thought processes akin to the hypothesized dimension, to justify use of scale values. For any given five-point hypothetical scale, there are a possible 120 ordered permutations. The unfolding model holds that for any given hypothesized scale only a small subset of the 120 ordered responses (I, or individual, scales) will be transitive (see Figure 4). In this context, "transitivity" means that the subject's response indicates they understood that the hypothesized construct lies along a continuum from A to E. This comes from the ideal point model, which takes into account the relative positions of the stimuli as well as their midpoints. For example, the person who provides the preference order BACDE has crossed the AB midpoint, so their ideal point is closer to B than to A. A person whose ideal point is located just to the left of the C item on the scale should give the preference order CDBAE, representing the individual's relative distance from the five points on the continuum. A response of CBEAD would indicate that the person is saying they think item E is closest to items B and C on the metric, which it is not. According to Coombs, in this instance the individual's score has "fallen off the metric," because their ordered response makes no sense given the underlying theory. Such a preference order is referred to as "intransitive." For any given five-point metric, there are only 11 transitive ordered (ordinal level) responses. If the true underlying metric is ABCDE, then the transitive responses are ABCDE, BACDE, BCADE, BCDAE, CBDAE, CDBAE, CDBEA, CDEBA, DCEBA, DECBA, and EDCBA. All other permutations are declared intransitive. Each metric has its polar permutations, which are exact reversals of one another. For example, the ABCDE metric has poles of ABCDE and its reverse, EDCBA.

Coombs maintains that if "50% plus one" of the experimental subjects' preference orders fall on the metric, the scale is reliable. He also maintains that for the responses to form a scale a reversal must be present. This simple approach to evaluating the metric can be attributed to the fact that advanced statistical packages did not exist when Coombs formulated his theory. Today, all possible metrics can be exam-

ined to determine whether the hypothesized one is the only sensible one. For any given five-point metric, only 60 possible competing models can fit the data.

Using the SAS (SAS Institute, 1985) programming language, programs were developed to evaluate every one of the 60 metrics and produce summary statistics. Partial output of the program is summarized in Table 1 for the 427 cancer patients. It must be noted that presence or absence of a reversal is now no longer a prohibiting qualification to acceptance of a metric. The program merely runs through each model and notes various statistics that can be used for verification purposes. It then ranks the models by the number of valid responses in the dataset, notes whether a reversal is present, and notes the number of empty cells in each model.

As illustrated in Table 1, the hypothesized ABCDE scale is the only model in which more than 50% of the respondents' answers correspond to one of its 11 transitive preference orders, or "cells." No cells are empty, which means that each of the 11 valid responses appeared at least once in the dataset. There was a reversal for the ABCDE metric in the dataset, which means that at least one observation was made at each of the two poles (ABCDE and EDCBA). This would suggest that cancer patients understand the hypothesized construct.

Table 1 *Rank Ordering of Competing Scale Models*

Scale	Name	Valid	Valid %	Invalid	Invalid %	Empty Cell	Reversal
1	ABCDE	282	66.0422	145	33.958	0	Y
6	ABEDC	184	43.0913	243	56.909	6	N
3	ABDCE	154	36.0656	273	63.934	2	N
4	ABDEC	128	29.9766	299	70.023	5	N
24	AEDCB	128	29.9766	299	70.023	4	N
2	ABCED	125	29.2740	302	70.726	7	N
60	DCBAE	104	24.3560	323	75.644	5	N
5	ABECD	96	22.4824	331	77.518	7	N
22	AECDB	85	19.9063	342	80.094	5	N
12	ACEDB	83	19.4379	344	80.562	5	N

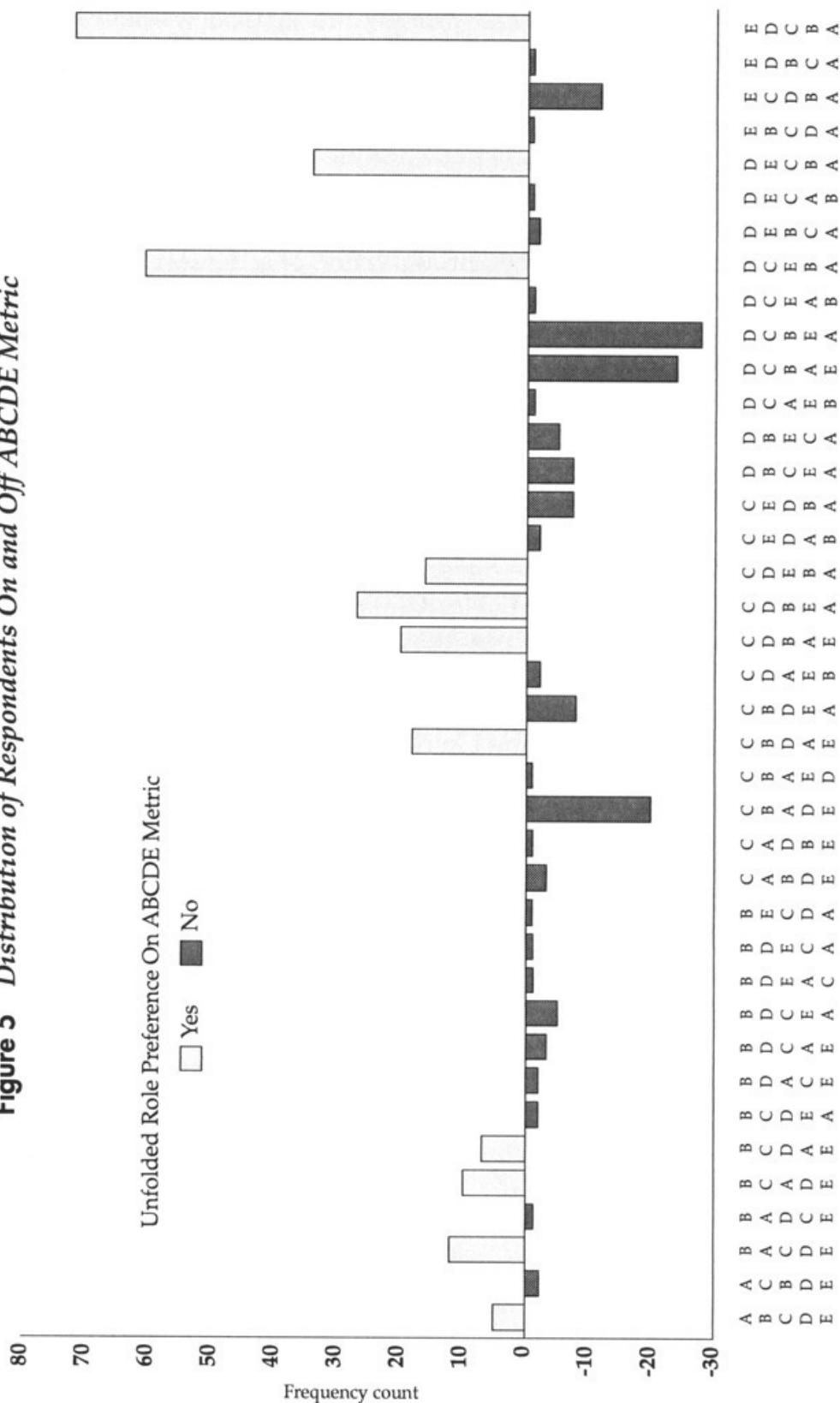
The only other metric that could possibly compete with the posited ABCDE scale is the ABEDC dimension. Although it fails to meet the criterion of 50% plus one, this possibility should be fully explored. Table 2 shows the respondents' detailed frequency distributions along the two competing metrics. The ABCDE metric has a reasonable distribution along its entirety, whereas the ABEDC metric is half empty. Coombs would reject this metric outright on the basis of his second criterion, because no reversal is present.

Table 2 Detailed Scoring of Competing J Scales		
Scale = 1		
Answer	Count	Percent
ABCDE	5	1.1710
BACDE	12	2.8103
BCADE	10	2.3419
BCDAE	7	1.6393
CBDAE	18	4.2155
CDBAE	20	4.6838
CDBEA	27	6.3232
CDEBA	16	3.7471
DCEBA	61	14.2857
DECBA	34	7.9625
EDCBA	72	16.8618
Scale = 6		
Answer	Count	Percent
ABEDC	0	0.0000
BAEDC	0	0.0000
BEADC	0	0.0000
BEDAC	0	0.0000
EBDAC	0	0.0000
EDBAC	0	0.0000
EDBCA	1	0.2342
EDCBA	72	16.8616
DECBA	34	7.9625
DCEBA	61	14.2857
CDEBA	16	3.7471

Once the ABCDE metric has been assessed as being sound, ordinal scale values from 1 to 11 can be assigned to subjects whose preference orders fell directly on the metric, and distributions and effects of covariates can be examined. Modelling is most easily and appropriately done via McCullagh's (1980) regression models for ordinal data. However, a major question remains: What to do with the people who responded "incorrectly"? Coombs (1976) suggests that such people, for the remainder of the analysis, should be dropped from consideration. However, the idea of discarding a substantial portion of a dataset is not appealing. Several methods are possible at this point. Figure 5 shows the distribution of respondents on and off the ABCDE metric. If one assumes that the people who fell off the metric made a mistake, such mistakes might naturally occur at random. This is clearly not the case for this distribution. Most of the mistakes occur in the area between items C and D on the scale, which suggests that these two stimuli were not a "just noticeable difference" apart in this sample and as a result subjects were likely to confuse them. One alternative would be to collapse items C and D and then redistribute the scores. Another would be to rank the preference orders from 1 to 120 (or the number observed out of the total possible number of ordered permutations) and proceed as if an ordinal variable had been observed. Either route would allow the investigator to retain all of the observations. More detail about this approach and analytic procedure is described in Sloan (1994).

A naturally occurring categorical variable is the person's most preferred role in treatment decision-making. For analysis purposes, five categories can be used (A, B, C, D, E), or preference orders can be reclassified into Active (A, B), Collaborative (C), and Passive (D, E). Another approach is to create a categorical variable based on the person's two most preferred roles: Active-Active (AB, BA), Active-Collaborative (BC), Collaborative-Active (CB), Collaborative-Passive (CD), Passive-Collaborative (DC), and Passive-Passive (DE, ED) (Hack, Degner, & Dyck, 1994). Ordinal categorical analysis associated with chi-square and other cross-tabulational measures can be applied to these data.

Figure 5 Distribution of Respondents On and Off ABCDE Metric



Clinical Applications

The CPS is also useful as a clinical-assessment tool. Two approaches have been developed for its application.

1. The "pick one" approach: Patients were interviewed privately prior to their first visit to the oncologist, as part of a nursing intervention (Neufeld, Degner, & Dick, 1993). They were asked to consider the five cards and select the one that fell closest to their preferred role in the treatment decisions to be discussed with their oncologist that day. Patients were able to read through the cards, which were laid out in an order ranging from most to least control, and select the one that best represented their preferred role in decision-making. Then they were asked to discuss the extent to which the statement on the card actually represented their preference. This is important in the clinical context, because an individual's ideal point might fall between two items. Many patients were surprised that they were offered this choice, thinking that they were just going to have to accept their physician's recommendation about treatment. Seeing the range of alternatives allowed them to think differently about participation in decision-making. The CPS has proven to be useful for eliciting input from patients and helping clinicians gain insight into patient preferences. More information about applying the CPS in this manner is available in the form of an audiotape and manual (Triclinica Communications, 1993).
- Fixed-order presentation of the cards by computer: The fixed-order presentation approach has been adapted for use on a touch-screen computer. After an introductory screen describes the task, two cards appear side by side on the screen in the fixed order described under Research Applications above. When the subject touches the screen at their preferred card, the next two cards automatically appear. At the end of the task, a printed diagram shows the patient's preferred level of involvement in decision-making on the keep/share/give-away control dimension (see Figure 2), with an arrow indicating their ideal point. This program is currently being evaluated in a clinical trial to determine whether women with breast cancer who are coached using this program and given the printout prior to their medical visit achieve a greater degree of involvement in treatment decision-making than women who are not coached using the computer program.

Preferred versus Actual Role in Decision-Making

Sutherland et al. (1989) used the original statements of Strull et al. (1984) in studying 60 radiotherapy patients at the Princess Margaret Hospital in Toronto. Patients were asked to select their preferred role in decision-making using the "pick one" approach described above, but they were also asked to indicate which role they had actually assumed in making treatment decisions. This approach was used in a recent study of women with breast cancer (Degner et al., 1997). Once the patient had completed the card sort and the result had been recorded, the five cards were laid out on a surface in the order the patient had picked. They were then asked to reconsider the order, and indicate the card that best represented the role they had played with respect to their original surgical treatment. Patients were able to easily distinguish between their preferred role and actual role in treatment decision-making.

Data Management and Analysis

Comparison of respondents' most preferred role and the role they believe they actually assumed in decision-making provides an important index of how consumers believe various settings are accommodating their preferences. While chi-square analysis gives an indication of whether there is significant incongruence between preferred role and actual role, displaying respondents' preferred and actual roles allows for more precise examination of the placement, direction, and extent of the incongruence. It could lie in the direction of being asked to make choices they prefer not to make, as well as in the direction of not achieving a satisfactory degree of involvement. The greater the distance between the individual's actual role and preferred role, the greater the incongruence.

This analysis approach is best illustrated in a recent survey of 1,012 women with breast cancer (Degner et al., 1997). Only 42% of all the women believed they had achieved their preferred role in decision-making for their initial surgical treatment. Analysis of incongruences between preferred role and actual role revealed that only 21% of the women who wanted the most active roles in decision-making achieved them. However, a small group of women (14.9%) believed they had been pushed to assume more decisional control than they wanted. This type of analysis is very useful in describing patients' perspectives on their experiences around decisional control in our health-care system. The potential to reduce discrepancies between preferred role and actual role in decision-making also provides an opportunity for evaluation of specific nursing interventions by measuring a specific outcome (Davison & Degner, 1997).

Samples Studied

To date, the CPS has been used with a variety of samples. The sample of 436 newly diagnosed cancer patients was compared to a sample of 482 members of the public who were asked to choose the role they would like to play in treatment decision-making if they were diagnosed with cancer (Degner & Sloan, 1992). While the majority of cancer patients (59%) wanted physicians to make treatment decisions on their behalf, most members of the public (64%) thought they would want to make their own treatment decisions if they got cancer. Other projects have involved testing the scale in smaller samples of newly diagnosed prostate-cancer patients (Davison et al., 1995) and newly diagnosed breast-cancer patients (Bilodeau & Degner, 1996; Hack et al., 1994). A larger study of breast-cancer patients at a variety of points in their disease trajectory found that 22% preferred an active role, 44% a collaborative role, and 34% a passive role in decision-making (Degner et al., 1997). Another study was undertaken, in Britain, with 150 women with newly diagnosed breast cancer and 200 women with benign breast problems (Beaver et al., 1996). The CPS has also been adapted to study preferences for decisional control in kidney dialysis (Kaprowy, 1991), in vitro fertilization (Thompson, 1990), and childbirth (Gupton, 1994).

Because the items in the CPS use general wording, they are applicable to a wide variety of health-related conditions. Alternatively, the items can be revised, and graphics developed, to suit the context under study. Determining the proportion of preference orders obtained in the new context that fall directly on the hypothesized dimension provides direct evidence about whether the revised stimuli form a scale.

Evidence for Validity and Reliability

The construct validity of the CPS was established by defining the construct in the context of a grounded theory, and, to date, the scale has proven a useful tool in epidemiological surveys whose goal is to establish estimates of the prevalence of different preferences and to determine the best predictors of these preferences. However, the usefulness of the measure in longitudinal as opposed to cross-sectional prediction remains to be established. Currently, work is being conducted to determine whether women with breast cancer who desire more involvement in decision-making at the time of diagnosis, and/or achieve more involvement, experience less anxiety, depression, and post-decisional regret three years post-diagnosis, as suggested by Fallowfield's long-term follow-up of breast-cancer patients in England (Fallowfield, Hall, Maguire, Baum, & A'Hern, 1994). This study also addresses the issue of

whether preferences change over time. Davison and Degner (1997) have already demonstrated that a nursing intervention to empower men with prostate cancer did allow the patients to assume more active roles in decision-making, as measured by the CPS, and also resulted in lower anxiety levels.

In each of the major studies undertaken with the control preferences scale in cancer populations, unfolding analysis has demonstrated that the scale has met Coombs's criterion of 50% plus 1 subjects falling on the hypothesized dimension (see Table 3). Similar results were obtained for members of the general public (56%). Given the fact that out of 60 possible scales that could emerge from $n=5$ stimuli, only one has met the scaling criterion in study after study, the CPS has demonstrated reliability in cancer populations. However, similar testing would have to be undertaken should the scale be used to estimate preferences in different populations or regarding health-care decisions other than those concerning medical treatment. As Table 3 demonstrates, method of presentation does influence the degree of measurement error, with random order being less satisfactory than the other two methods in a research context. Indeed in Beaver et al.'s (1996) study of 200 women with benign breast disease, which used random-order presentation, only 49% of subjects fell on the ABCDE dimension; the study thereby failed to meet this reliability criterion.

Table 3 *Reliability of the CPS with Cancer Patients*

Criterion	Study	Sample	Sample size	Percent on dimension	Method of presentation
50% plus one subjects fall on hypothesized dimension ABCDE	Degner & Sloan (1992)	Newly Diagnosed (mixed)	436	66%	Every subset of two
	Beaver et al. (1996)	Newly Diagnosed (breast cancer)	150	58%	Random order
	Degner et al. (1997)	Any point in Disease Trajectory (breast cancer)	1,012	63%	Fixed order

Discussion

Early attempts to understand consumer preferences took a dichotomous approach, asking subjects to select one of two statements as their preferred role in health-care decision-making: either "I prefer to participate in decisions about my medical care and treatment" or "I prefer to leave decisions about my medical care and treatment up to my doctor" (Cassileth, Zupkis, Sutton-Smith, & March, 1980). Subsequently, Likert scaling was used with investigator-selected items to measure the

general desire for control in health care (Greenfield et al., 1985; Krantz et al., 1980; Smith, Wallston, Wallston, Forsberg, & King, 1984). A variant of this approach was taken by Ende, Kazis, Ash, and Moskowitz (1989), who used a five-point rating scale with six general items and three items related to each of three hypothetical health problems, for a total of 15 items. Other investigators have used a "pick one" approach with three or five statements similar to ones on the physician-patient dimension of the CPS (Larsson, Swardsudd, Wedel, & Saljo, 1989; Strull et al., 1984; Sutherland et al., 1989), or a Q-sort in which one factor was described as "decisional control" (Dennis, 1987)

The CPS offers several advantages over previously published measures. First, the data can be presented in a manner that is easily understood by clinicians. Distributions of subjects along the control preferences dimension provide more meaningful information to guide clinical practice than do mean values. Second, the CPS scale values can be used with regression models for ordinal data. As a result, the scale offers the same advantage as Likert scaling in determining the effect of covariates, and is an improvement over the "pick one" approach, in which the effect of covariates can be examined only on a univariate basis. Third, examination of all preference orders allows for the emergence of competing metrics that could offer other explanations of consumer preferences in subsets of the populations under study. Fourth, the CPS can identify the degree of congruence or incongruence between preferred role and actual role. Finally, the CPS has been demonstrated to be useful as a clinical screening tool as well as a research measure.

The use of a "pick one of two statements" approach may lead to inaccurate conclusions both about distributions of preferences and about the effects of covariates on consumer preferences. Previous studies (Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Casselith et al., 1980) may have seriously overestimated the proportion of people who want to participate in treatment decision-making, simply because of the limited number of stimuli presented to subjects. Investigators using the "pick one of two statements" approach have concluded that age and education are related to consumer preferences, with younger, more highly educated people wanting more control in treatment decision-making. While this univariate effect is also reported by investigators using scaled data, both the Ende et al. (1989) study using a Likert scale and our study using the CPS (Degner & Sloan, 1992) found that less than 15% of the variance in preferences was accounted for by any predictive model. The use of characteristics such as age and education level to judge an individual's role preferences clearly could be misleading and potentially cause stereotyping of subgroups.

Individual assessment of consumer preferences using a screening measure such as the CPS remains the best clinical approach, and one that is currently being evaluated in the context of a clinical trial.

Previous intervention studies to enhance consumer control in health care have largely proceeded from the assumption that all subjects want to exercise decisional control. As a result, few attempts have been made to examine the possible interaction effect between control preferences and the opportunity to participate in making choices on health-care outcomes (Wallston et al., 1991). Congruence between preferred role and actual role may be more important than the actual assumed role (Haug & Lavin, 1981). The CPS provides a quick and practical approach to blocking subjects in order to examine the interaction effect of control preferences and control-enhancing interventions on outcomes.

The CPS offers a new approach to eliciting consumer preferences about participating in health-care decision-making. The scale has been used by hundreds of people, ranging from members of the general public to members of highly stressed populations, and has proven to be easily and quickly administered. Even people with relatively low levels of education can successfully complete the paired comparisons. Scaling procedures have demonstrated that people in a variety of populations do have systematic preferences about keeping, sharing, or relinquishing control over health-care decisions. The CPS should prove to be a useful measure for both clinicians and researchers as they attempt to foster consumer involvement in a manner that leads to improved health-care outcomes and better utilization of scarce resources.

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Requests for reprints should be addressed to Dr. Lesley Degner, St. Boniface General Hospital Research Centre, 351 Taché Avenue, Winnipeg, Manitoba R2H 2A6 Canada.

Investigating Patients' Preferences for Different Treatment Options

Hilary A. Llewellyn-Thomas

Cet article offre un aperçu de deux approches méthodologiques utilisées pour cerner les préférences du patient en matière de traitement. La première approche est issue de l'analyse de décision formelle et est grandement recommandée dans le cadre de l'élaboration de politiques sur la santé et de principes directeurs pour les activités cliniques. Selon l'argumentation de l'auteur, l'utilisation de cette approche n'est pas nécessairement appropriée en ce qui a trait au comportement d'un individu face à la prise de décisions. L'auteur présente la conceptualisation, le développement et l'application d'une autre approche qui permet de quantifier les préférences relatives du patient face à un traitement. Cette approche – le «compromis de probabilités» – peut être structurée pour illustrer, de manière très graphique, les véritables dilemmes complexes auxquels les patients doivent souvent faire face. Les étapes de cette approche peuvent être présentées de manière à aiguiller le patient vers un démarche par le biais de laquelle il examinera, de manière explicite, les compromis possibles. Étant donné les éléments visuels et interactifs de cette approche ainsi que sa bonne performance jusqu'à présent, le compromis de probabilités semble être une technique particulièrement prometteuse, non seulement pour intégrer les préférences des patients dans la conception d'essais cliniques mais aussi pour aider les patients à comprendre d'importantes données probabilistes. Ces données peuvent être alors utilisées pour clarifier les valeurs des patients et les communiquer à l'équipe soignante. Les futures étapes de ce travail cumulatif seront consacrées à la vérification d'hypothèses selon lesquelles la technique de compromis de probabilités est vraiment efficace dans l'exécution de cette fonction.

This paper provides an overview of two methodologic approaches to investigating patients' treatment preferences. The first approach is derived from formal decision analysis, and is widely advocated for formulating health policy and constructing clinical guidelines. The author argues that it may not be suitable for application in the context of individuals' decisional behaviour, and then describes the conceptualization, development, and application of an alternative approach to quantifying patients' relative treatment preferences. The approach — the "probability trade-off" — can be structured to illustrate in a highly graphic way the actual complex dilemmas patients often face, and its procedures can be arranged so as to engage the patient in explicitly considering the trade-offs involved. Given these visual and interactive characteristics, and its performance to date, the probability trade-off seems to be a particularly promising technique not only for incorporating patients' preferences into the design of clinical trials, but also for helping patients to comprehend important probabilistic information and then use that information to clarify and communicate their values to the health-care team. The future phases of this cumulative work will be devoted to testing hypotheses that the probability trade-off technique actually can fulfil this function.

Hilary A. Llewellyn-Thomas, R.N., B.Sc., M.Sc., Ph.D., is Professor, Faculty of Nursing, University of Toronto, and Senior Scientist, Clinical Epidemiology Unit, Sunnybrook Health Science Centre, Toronto.

Introduction

In health care, empirical enquiry into patients' decisions is motivated by current debates about resource allocation, rising consumerism, increasing complexity of choice, and the ethical imperative to foster, in appropriate ways, autonomous and informed patient decision-making (Llewellyn-Thomas, 1995; O'Connor, Llewellyn-Thomas, & Drake, 1995). Keeney (1992) argues that a person's decisions are ultimately determined by his or her values or preferences. In the context of health care, "preference" refers to the degree of satisfaction or desirability that a person attributes to a particular decision-making role or style (Degner & Russell, 1988; Pierce, 1993), to a particular state of health (Froberg & Kane, 1989; Llewellyn-Thomas, 1996), to a particular time period (Llewellyn-Thomas, Williams, & Arshinoff, 1994; Palda et al., 1994a; Palda, Llewellyn-Thomas, MacKenzie, Pritchard, & Naylor, in press), or to a particular treatment process (Levine, Gafni, Markham, & MacFarlane, 1992; Liao et al., 1996; O'Connor, Boyd, Warde, Stolbach, & Till, 1987; O'Connor, Tugwell, & Wells, 1994).

This paper will concentrate on the empirical investigation of patients' strength of preference for various treatment options. The different disciplines represented by anthropologists, ethicists, cognitive scientists, and economists use a wide variety of empirical approaches to investigate these preferences; for the purposes of this paper the techniques derived from economics merit focused attention because they are becoming widespread in health-services research (Hammond, McClelland, & Mumpower, 1980; Llewellyn-Thomas et al., 1992).

There are two general strategies that could be used to reveal relative strength of preference for various treatment options. The first approach is formal decision analysis (described below). In health research, it is traditionally used when the purpose is to quantify a *group's* strength of preference for different treatment options in order to devise health policies or treatment guidelines. Decision analysis has a strong axiomatic basis and is an extremely powerful and appropriate approach that primarily serves the needs of the clinician or policy-maker facing decision problems involving patient populations.

Because of its successful application in the aggregate context, there has been a tendency on the part of investigators to assume that formal decision analysis can also be used to help *individual* patients with the process of "values clarification" (O'Connor, 1993). The purpose of this paper is to challenge this assumption, to argue that exclusive reliance

on formal decision analysis would be unwieldy in the context of working with individual patients, and to present an alternative approach. This second approach — the probability trade-off technique — is emerging in the research literature. It is designed to reveal an *individual's* strength of preference as part of the process of providing decision support within the clinical context. The first approach will be merely outlined here, since it is described in depth elsewhere; the primary focus of this paper will be the rationale, construction, and application of the second approach.

The Group Perspective: Using Traditional Decision Analysis

As noted above, the formulation of health policy or the construction of clinical guidelines often requires health-care decision-makers to identify and prescribe a treatment plan for groups of patients. Formal decision analysis has traditionally been used to satisfy this prescriptive need.

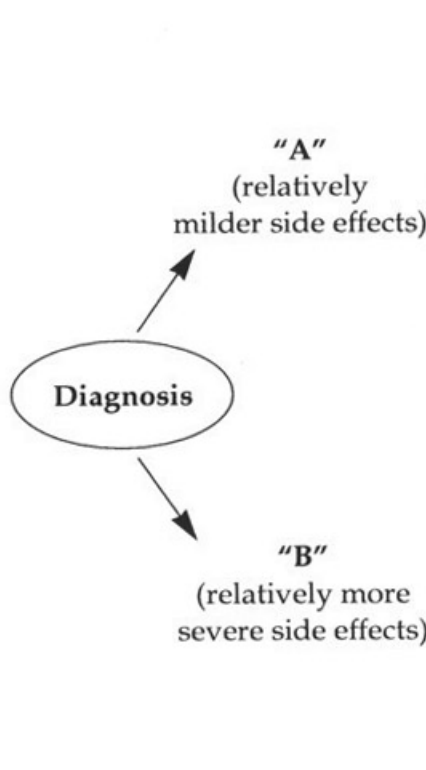
The Steps in Decision Analysis

The overall structure of a decision analysis is illustrated in Figure 1. This example has been distilled to the barest outline in order to present the general principles of the approach; the reader seeking greater detail on the procedures and their rationale should consult a formal text in clinical decision analysis (Sox, Blatt, Higgins, & Marton, 1988; Weinstein & Fineberg, 1980).

A decision analysis begins with construction of a formal decision analytic "tree," which specifies the various outcome health states (e.g., X, Y, and Z) that could be obtained from the different treatment options under consideration (e.g., Treatment A, with moderate side effects, or Treatment B, with serious side effects).

Then, the likelihood or probability that a particular treatment option will lead to each of the health states is estimated. (For example, in our illustration, given Treatment A, the chances of entering states X, Y, and Z are 0.30, 0.55, and 0.15, respectively; with the more intrusive Treatment B, the chances of entering states X, Y, and Z are 0.70, 0.10, and 0.20, respectively.) These probabilistic estimations often are obtained from the clinical literature on the particular health-care problem.

Figure 1 *Clinical Decision Analysis: An Example*

Available Treatments	Probabilities of Various Outcomes	Utilities for Outcomes
 <p>"A" (relatively milder side effects)</p> <p>Diagnosis</p> <p>"B" (relatively more severe side effects)</p>	<p>X (p=.30)</p> <p>Y (p=.55)</p> <p>Z (p=.15)</p> <p>X (p=.70)</p> <p>Y (p=.10)</p> <p>Z (p=.20)</p>	<p>.75</p> <p>.60</p> <p>.20</p> <p>.75</p> <p>.60</p> <p>.20</p>
<p>"Expected Utility" for Treatment A = (.30) (.75) + (.55) (.60) + (.15) (.20) = .585</p> <p>"Expected Utility" for Treatment B = (.70) (.75) + (.10) (.60) + (.20) (.20) = .626</p>		

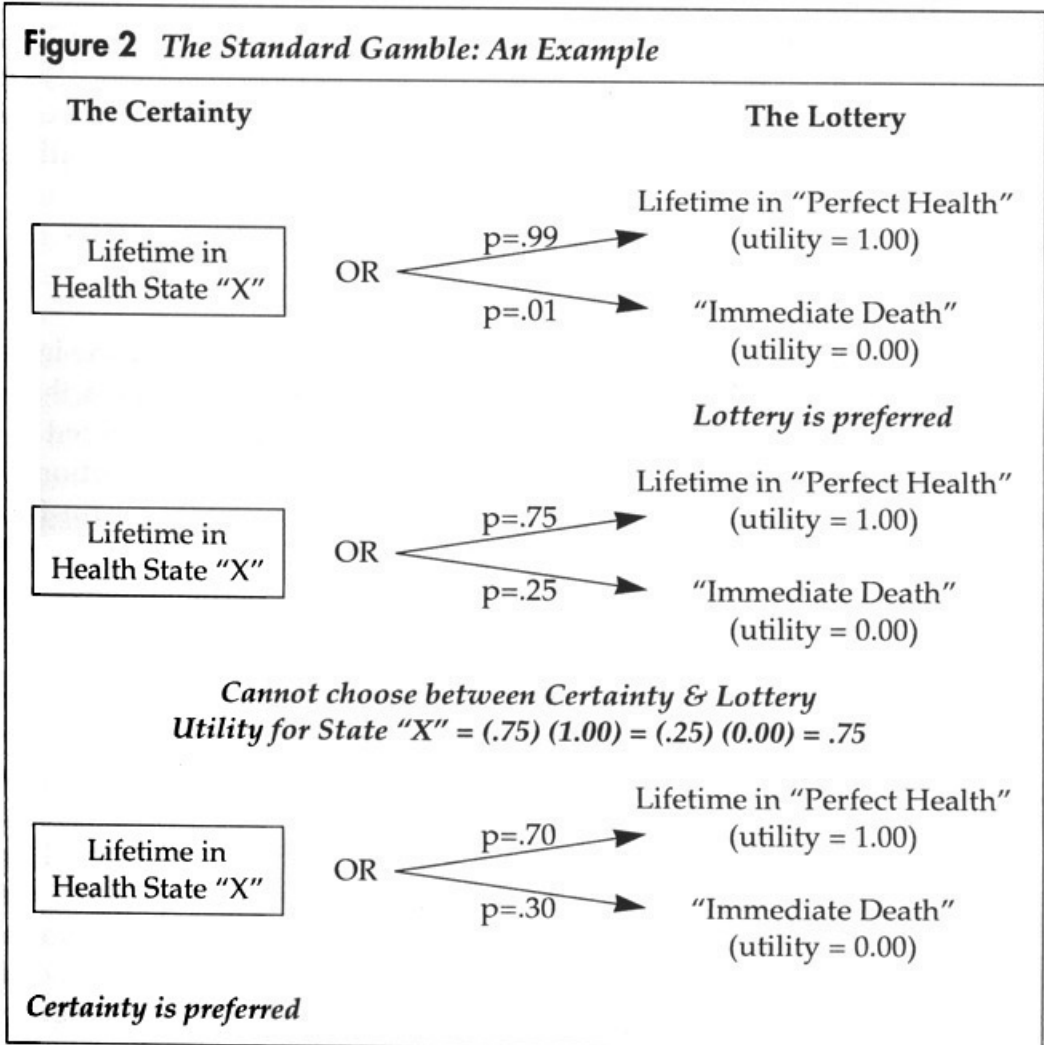
Next, subjective evaluations of the relative desirability of each outcome health state are estimated, often using the judgements of groups of relevant raters. There are a number of ways to elicit these evaluations (see Froberg & Kane, 1989), but the standard gamble, a technique that generates "utilities," is considered the criterion method (Llewellyn-Thomas et al., 1982; Llewellyn-Thomas et al., 1984; Sox et al., 1988; Weinstein & Fineberg, 1980).

Suppose we are interested in obtaining the utility score for health state X for a group of raters. The standard gamble procedure for doing this is outlined in Figure 2. The procedure begins with asking a rater to consider a hypothetical choice between the certainty of a lifetime continuously in state X and a hypothetical lottery. The lottery has two possible outcomes. The positive outcome is a much better health state,

arbitrarily assigned a utility of 1.00. The negative outcome is a much worse health state, arbitrarily assigned a utility of 0. The probabilities in the lottery are systematically altered until the rater cannot choose between the certainty of continued life in state X and the lottery. Thus, as in the example presented in Figure 2, suppose the rater indicates that he or she cannot choose between the certainty of continued life in state X and the lottery when the chance for Perfect Health is .75 and the risk of Death is .25.

At this point, the lottery's expected utility is $(.75)(1.00) + (.25)(0.00) = .75$. According to the axioms of rationality that underlie the standard gamble, the expected utility of this lottery is, by substitution, the utility for health state X. Thus, in our example, for this rater the utility score for health state X is .75. (Note that this utility score can range from 0 to 1.00, with higher scores indicating a relatively more desirable health state.)

Figure 2 *The Standard Gamble: An Example*



Since health-policy decision problems often require comparisons across decision analytic trees for different diseases or illnesses, a common scale for outcome evaluations is necessary to permit such later comparisons. Standard gamble utilities are particularly useful in this regard, since, if they are obtained using "Good Health" and "Death" as the gamble anchors, they can be considered to rest on this common scale.

The standard gamble steps are then repeated for each of the other outcome states in the decision tree. The entire process is repeated for the full sample of raters to yield a distribution of utility scores for each outcome state. Then the sample's mean utility scores (e.g., .75 for state X, .60 for state Y, and .20 for state Z) are incorporated into the decision model and are used in conjunction with the associated probabilities to compute the expected utility of each treatment option. See Figure 1 for an example of these computations for a particular hypothetical decision tree. Thus the expected utility for a treatment arm in a decision analytic tree is a proxy measure of the group's overall strength of preference for that treatment. Finally, the option with the highest expected utility is identified as the "best" overall treatment strategy for the aggregated patient population facing the particular health-care problem.

The Limits of Decision Analysis

Figuratively speaking, in formal clinical decision analysis the investigator stands at the outcome end of the decision tree, looks back through the tree using probabilistic and evaluative information gathered in the past to compute the expected utility of each treatment option, and draws conclusions about what the decision "should" be for future patients in the same clinical situation. For the policy-maker or clinical investigator who is studying decision problems involving patient populations, this can be an extremely powerful and appropriate approach, provided careful attention is paid to a few caveats (Llewellyn-Thomas, 1996).

First, decision analysis requires philosophical and scientific justification for using aggregated data about probabilities and utilities. In addition, in any particular clinical decision analysis some methodologic issues associated with the standard gamble need to be satisfactorily addressed. One of these is the fact that the technique is more tractable when the outcome health states in the tree are stable, chronic conditions. Other issues include whether evaluations should be obtained from the general public or from groups of patients actually experienc-

ing the outcome states, and which measure of central tendency should be used in aggregating a group's utilities. A further issue is the interpretation of the highly skewed utility distributions that are generated by the standard gamble when the health state under consideration is not life-threatening and yet "Death" is used as a gamble outcome. (These issues are discussed in more detail in Nichol, Llewellyn-Thomas, Naylor, and Thiel, 1996.)

However, even when these issues are resolved, the applicability of decision analytic techniques is questionable when the research objective is not to resolve a health-policy question, but to understand and help an individual patient who is making an actual decision about his or her care. The perspective on the decision problem is different. The individual is formulating and reporting his or her preferences for different processes of care that will take place in real time, that will involve differing effects on health-related quality of life, and that will lead to outcome states that are themselves transitory. In this context it is very difficult to use conventional utility assessment approaches to elicit evaluations for these outcomes, since the standard gamble is less tractable for transitory treatment-induced health states. Furthermore, an individual's decision behaviour often is congruent not with the axioms of "rational" choice, but rather with the personal meaning he or she attributes to the situation (Fischhoff, Goitein, & Shapira, 1982; Llewellyn-Thomas, Williams, Levy, & Naylor, 1996; Schoemaker, 1980, 1982). Accordingly, one could challenge the validity of using the prescriptive technique of decision analysis to describe and support individualized decision-making. Given these concerns, it may be inappropriate to take techniques originally designed for formal decision analysis and use them to evaluate the effectiveness of individuals' actual decision-making or to serve as a clinical decision aid for individuals. The results generated by such a method/purpose "mis-match" may be irrelevant or, worse, misleading.

Elsewhere, an argument has been presented for using a different approach under these circumstances (Llewellyn-Thomas, 1994) when a patient wishes to be involved in shared decision-making about his or her care (Deber, Kraetschmer, & Irvine, 1996; Degner & Russell, 1988; O'Connor et al., 1995). This approach deliberately works with the fact that an individual patient in real time stands at the actual decision point of treatment selection, and, while figuratively looking down the decision tree, considers the side effects of the various treatment options, the possible outcomes of treatment, and the probabilities of obtaining those outcomes. We refer to this approach as the "probability trade-off technique" (Llewellyn-Thomas et al., 1996).

The Individual's Perspective: Using the Probability Trade-off Technique

Steps in the Probability Trade-off Technique

The general characteristics of this approach are best outlined in the two-treatment situation. First, the patient is presented with descriptive and probabilistic information about the protocols, side effects, and potential benefits associated with two clinically reasonable alternatives — for example, treatments A and B. These “bits” of information are presented sequentially and arranged in pairwise columns to permit gradual assimilation of the information as well as clear comparisons. In addition, devices such as moveable pie charts are used to foster comprehension of the probabilistic information. In effect, once the full decision situation has been mapped out, the respondent is involved in learning about a combined process-and-outcome path that includes descriptions of what the treatments would entail, their possible outcomes, and the probabilities of encountering those outcomes.

Then the respondent is invited to indicate which treatment option would be preferable, given this “map.” To illustrate, suppose the respondent initially chooses Treatment A. Next, the interviewer systematically either reduces the probability of benefit from Treatment A or increases the probability of benefit from Treatment B, until the respondent switches his/her stated preference to Treatment B. On the other hand, if the respondent originally chooses Treatment B, the interviewer either reduces the probability of benefit from Treatment B or increases the probability of benefit from Treatment A, until the respondent switches his/her stated preference to Treatment A. Usually, a visual sliding scale is used to demonstrate these imaginary increments/decrements in probability.

When this systematic alteration is carried out, the probability of benefit obviously becomes less and less clinically reasonable and more and more hypothetical in nature. This is made clear to the respondents, who are told that these alterations in the decision problem are a device for assessing how strongly they feel about their original choice. Thus one who highly values his original choice will not switch to the alternative until either the benefit from his original choice is considerably reduced or the benefit from the alternative is considerably increased.

It is critically important that the following points about this general procedure be emphasized. The benefit that is probabilistically altered (e.g., chance of symptomatic relief, reduced risk of an adverse event,

reduced risk of recurrence, or chance of survival), and the direction in which it is changed, are not determined by the interviewer on an ad hoc basis at the time of data collection. These design elements are established by the investigator beforehand, according to the clinical context and the particular nature of the research question.

For example, suppose the research objective is to quantify the strength of preference for one of the two treatment alternatives — let us say Treatment B relative to Treatment A. Such a situation would arise when Treatment A is the standard for care, Treatment B is a newly introduced mode of therapy, and it is important that patients' attitudes toward this new treatment option be determined. This kind of probability trade-off task is illustrated in Table 1, which uses an example from preventive lifelong medication for hypercholesterolemia. Note that in this particular example the procedure begins with a "dominated" choice, in that the standard Treatment A is preferable, since nothing is to be gained from Treatment B. The patient logically chooses Treatment A. Then the probabilistic risk of a future negative event is systematically reduced (thus in this context the probability of benefit is increased) until the respondent's preference switches from Treatment A to Treatment B.

The switch point can then be used as a measure indicating the "relative" strength of preference for Treatment B. (We use the term "relative" here to indicate that the technique determines the respondent's strength of preference for the option of interest [B] *in comparison to the other option* [A], rather than on an absolute scale anchored with "Good Health" and "Death.") Thus a person with a relatively weak preference for Treatment B will not accept it until the benefit has been greatly increased, whereas a person with a relatively strong preference will abandon Treatment A and switch to B as soon as a potential benefit is offered.

The above example refers to a preventive health-care situation. Another example would be a situation involving therapy for a life-threatening condition like cancer. In such a situation, the procedure also might begin with a "dominated" choice, in that the standard Treatment A is deliberately presented as preferable and the patient logically makes that initial selection. However, in this context the investigator might systematically increase the chance of long-term survival (i.e., in this context the probabilistic chance of a future positive event is increased) until the respondent's preference switches from Treatment A to Treatment B.

Table 1 *The Probability Trade-off Technique:
An Example in Preventive Health Care*

<p>Treatment A</p> <p>Protocol:</p> <ul style="list-style-type: none"> • Not eating foods high in saturated fat and /or cholesterol • No medication • See your doctor and have your blood checked about 3 times a year for the first year and at least once a year thereafter <p>Possible Side Effects:</p> <p>None</p> <p>Chance of Heart Attack:</p> <p>40 out of 1,000 people may have a heart attack (which may or may not be fatal) at some time over the next 10 years</p>	<p>Treatment B</p> <p>Protocol:</p> <ul style="list-style-type: none"> • Not eating foods high in saturated fat and /or cholesterol • A medication without cost to you: 1–2 capsules taken 1–2 times/day now and for the rest of your natural life • See your doctor and have your blood checked about 3 times a year for the first 2 years and at least twice a year thereafter <p>Possible Side Effects: (many of which will lessen in time)</p> <p>More frequent: (experienced by about 60 out of 1,000 people)</p> <ul style="list-style-type: none"> – constipation, muscle aches or cramps <p>Less frequent: (experienced by 10–30 out of 1,000 people)</p> <ul style="list-style-type: none"> – diarrhea, heartburn, nausea, headache, dizziness, skin rash, unusual tiredness or weakness <p>Chance of Heart Attack:</p> <p>40 out of 1,000 people may have a heart attack (which may or may not be fatal) at some time over the next 10 years</p> <p><i>Treatment A initially chosen</i></p> <p><i>Chance of heart attack then lowered (i.e., to 35/1,000... 30/1,000... 25/1,000) until respondent switches to choosing Treatment B</i></p>
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Thus the particular clinical context determines the option of interest, the benefit that is probabilistically altered, and the direction in which the task proceeds. Therefore in each application of the technique (see below) the underlying preference scale is idiosyncratic to the original decision problem. This would be a serious liability if we tried to apply the probability trade-off technique to decision analyses of health-policy problems that require an absolute preference scale permitting across-disease comparisons. However, when the research problem requires us only to assess individuals' strength of preference for A relative to B, within the confines of the particular clinical context, the disease-dependent nature of the scale is not a concern.

Whether the measurement technique generates internally consistent results is of greater importance. In one context, test-retest reliability coefficients ranged from .78 to .94 (Percy & Llewellyn-Thomas, 1995); in another, Brundage, Feldman-Stewart, Groome, and Davidson (1995) report similarly high test-reset reliability coefficients. This evidence implies that, in situations in which the underlying values are not expected to be labile, patients report reasonably stable switch points. However, since the relative preference scales are uniquely determined by the particular trade-offs in each decision problem, we cannot talk in terms of *the* psychometric properties of the technique as if they were characteristics that carry across all applications.

Past and Current Applications of the Probability Trade-off Technique

This general approach has been adapted for research problems that required measuring the relative strength of preference scores for a variety of treatments. The therapies have included chemotherapy (Llewellyn-Thomas, McGreal, Thiel, Fine, & Erlichman, 1991; O'Connor et al., 1987), radiation therapy (Llewellyn-Thomas, Thiel, & Clark, 1989; Palda et al., 1994b), the "Do Not Resuscitate" order (Percy & Llewellyn-Thomas, 1995), and lifelong medication for hypercholesterolemia (Llewellyn-Thomas, Paterson, Carter, & Naylor, 1994) and hypertension (Llewellyn-Thomas, Carter, Paterson, & Naylor, 1995).

Note that different research questions underlay each of these unique contexts. An early chemotherapy application assessed the treatment preferences of respondents indicating whether they would enter a clinical trial comparing the therapies of interest. Such investigations are noteworthy because different treatment attitudes held by those who would refuse trial entry would have implications for the transfer of the results of the clinical trial itself into general clinical practice (Llewellyn-Thomas et al., 1991). Other studies have explored the potential of the

probability trade-off technique as an innovative approach to teaching about probabilities, in the process of obtaining informed consent for trial entry (Llewellyn-Thomas et al., 1989) and for end-of-life decisions (Percy & Llewellyn-Thomas, 1995). These applications indicate that the technique may be helpful in revealing hidden ethical dilemmas in value-laden health-care situations.

More recently, we have used the probability trade-off technique to make explicit the "demanded risk reduction" for cardiovascular events that patients with asymptomatic hypercholesterolemia (Llewellyn-Thomas, Paterson, et al., 1994) or moderate hypertension (Llewellyn-Thomas, Carter, et al., 1995) would want before they would consider lifelong cholesterol-lowering or antihypertensive medication to be worthwhile. These investigations indicate that a substantial proportion of each of the relevant populations wants more risk reduction than is actually achievable from medication, but is not aware of the discrepancies. The existence of such sub-groups points to the need for decision aids that can incorporate patients' individualized risk factors and make explicit their achievable risk reduction, given various modifications in their risk profile.

In all of these earlier applications, the probability trade-off technique was confined to dichotomous choices, because the investigators were determining the strength of preference for an option of particular interest relative to its alternative. Recently there has been increased interest in applying the technique to situations that involve three different treatments, because these situations are not uncommon (for example, medical treatment, PTCA, and CABG for angina) and their complexity is likely to generate decisional conflict (O'Connor, 1993, 1995; O'Connor & D'Amico, 1990). This three-way application of the probability trade-off technique has been attempted with men with benign prostatic hyperplasia (Llewellyn-Thomas et al., 1996). It was able to identify patient sub-groups with unique orders of preference for watchful waiting, alpha blockers, and transurethral resection of the prostate, as well as identify individuals who reported close preference scores and therefore could be liable to experience decisional conflict. (Note that O'Connor and D'Amico, and O'Connor [1993, 1995], have argued that the concept of decisional conflict is particularly germane to nurses in clinical practice who may be involved in helping patients cope with the tensions induced by having to make difficult health-care choices for either themselves or dependent others.)

Besides its potential usefulness for exploring the role of preferences in individuals' treatment choices, probability trade-off is a promising device for estimating the feasibility of clinical trials in which health-related quality of life is a serious consideration. We have used an example from cardiology to illustrate how the general approach could be adapted to the task of estimating clinically important differences from the patients' perspective (Naylor & Llewellyn-Thomas, 1994). The task could be readily structured so as to identify the point at which potential participants think that the chance of benefit offered by a new treatment would be worthwhile, given a particular level of toxicity or side effects. This information would, in turn, be used to help estimate how many patients would need to be randomized in a clinical trial for reliable detection of a meaningful difference in outcome, if it exists as a result of the new treatment. Thus patient-identified clinically important effect sizes could be used in the computation of overall sample sizes for treatment trials; given these estimates, one could then readily determine whether the accrual of such sample sizes would be feasible in the particular clinical situations.

This logic also could be flipped another way. The task could be structured so as to identify the point at which potential participants think that an increased probability of toxicity or side effects offsets the chance of greater benefit offered by a new treatment. For example, hormone replacement therapy (HRT) traditionally has been considered to be contraindicated for women with breast cancer. Recently, given the long-term survival of women with early-stage breast cancer, concern has been developing that these women should be offered the protective long-term benefits of HRT in terms of decreased chances of cardiac disease and osteoporosis. The dilemma has led to arguments for launching a clinical trial to specify the degree of protection available to these patients. However, it is not known whether the accrual rates for such a trial could be successfully achieved. Currently, the probability trade-off technique is being used to answer this question (Pritchard, Llewellyn-Thomas, Lewis, Franssen, & Sawka, 1996). It is designed to determine the "maximal acceptable risk increment" in the chance of recurrence that women with a primary diagnosis of early-stage breast cancer would contemplate before accepting HRT, given its putative benefits (Bluming, 1993; Pritchard, Roy, & Sawka, 1995). If the overwhelming majority of these women report they would accept no incremental risk at all, then the prospects for successful recruitment into a future trial would look dim; it would be helpful to learn about this possible problem prior to funding and launching a large clinical trial.

Future Applications of the Probability Trade-off Technique

Some of the pressures behind the current interest in assessing patients' treatment preferences have been outlined in the Introduction. These pressures are most keenly felt in clinical situations in which there is much at stake for the patient but, because the results of clinical research are inconclusive, there is a "grey zone" of uncertainty about what is the "best" treatment to select (Naylor, 1995). In these uncertain situations, efforts are being made to develop and test techniques to help patients who wish to become actively involved in decision-making regarding their treatment (O'Connor et al., 1995).

These techniques differ in a number of ways from traditional patient-education programs (Llewellyn-Thomas, 1995). The factual treatment information they present is tailored to the particular patient's characteristics and is embedded in judgement tasks that promote comprehension and "values clarification." These values-clarification tasks are designed to engage patients in the active formulation and articulation of their personal preferences so that they, in turn, become readily apparent not only to the patient but also to other members of the health-care team.

There are several kinds of values-clarification tasks, including Dolan's analytic hierarchy process (Dolan, 1995), O'Connor's balance scale (O'Connor et al., 1994; O'Connor, Tugwell, et al., in press) and the probability trade-off proposed here. Research programs focusing on the effectiveness of the trade-off task for fostering informed consent to either accept or refuse treatment have just got underway in Canada, beginning in the field of oncology (Brundage et al., 1995; Brundage, Davidson, & Mackillop, 1997). The initial steps have involved examining the stability of patients' responses to the task itself. To date, the results are encouraging; this team of investigators reports reliability coefficients ranging from 0.82 to 0.94 (Brundage et al., 1995). The next steps in this programmatic approach could be either basic or applied in nature.

Basic studies would ask research questions about the processes that occur when the patient engages in this kind of values-clarification exercise. For example, are patients' responses vulnerable to hidden biasing effects? In earlier work in the decision sciences, people have been asked to consider *simulated* health situations in which differential "frames" (i.e., "a 10% chance of death" is a negative frame, whereas "a 90% chance of survival" is a positive frame) are applied to *extreme probabilities*. The early experiments demonstrated that these different presenta-

tions can induce strong "framing" effects influencing the selection of a treatment option (McNeil, Pauker, Sox, & Tversky, 1982; O'Connor, 1989; O'Connor et al., 1985; O'Connor, Pennie, & Dales, 1991). Although no systematic attempts have been made to test for a framing effect in the probability trade-off technique, we could hypothesize that such an effect will not appear. This prediction is based on two inter-related points: (a) since the probability trade-off task is individualized for the patient, it works with *realistic* probabilities and is by definition *highly salient* to the respondent; and (b) there is evidence that, when patients are asked to consider differentially-framed information about realistic probabilities in highly salient decision situations, such framing effects will not emerge (Llewellyn-Thomas, McGreal, & Thiel, 1995).

The effect that is more likely to become apparent is an "anchoring bias," induced by the fact that the trade-off technique, in narrowing down on the switch point, requires a series of choices. In some clinical contexts, the trade-off procedure could move from either a loss position toward a relative gain or a gain position toward a relative loss. We have some evidence that the sequential direction taken to identify the switch point may induce a biasing effect (Percy & Llewellyn-Thomas, 1995); however, this effect emerged in a life-and-death clinical decision situation and may not hold in, say, a preventive decision for a chronic, non-life-threatening context. In any case, the evidence to date implies that care should be taken to achieve internal consistency in the sequential direction that is taken to identify the switch point — unless the investigator is primarily interested in deliberately generating and exploring such an effect (in which case it becomes a main effect rather than a "bias").

Cognitive scientists, for example, would be intrigued by these basic questions, which are concerned with the fundamental processes of interpreting probabilistic information and formulating preferences. On the other hand, clinical investigators and health-care policy-makers might consider these issues too esoteric, and be far more interested in study designs comparing the trade-off task to usual practice (and/or to the other formal values-clarification exercises), in terms of its effectiveness.

There are a number of key philosophical and methodologic issues to consider when designing such evaluative projects, not the least of which is the selection of the outcome variable to be used as a measure of effectiveness (Llewellyn-Thomas, 1995; O'Connor, Llewellyn-Thomas, et al., 1997). Various disciplines may have different views about the relative importance of behavioural, cognitive, or attitudinal

outcomes such as the patient's actual treatment selection and subsequent adherence to therapy, comprehension of the information provided, or satisfaction with the decision-making process and level of decisional conflict. In this regard, O'Connor's operational definition of "satisfactory decision-making" — that is, a decision process that is informed, consistent with personal values, and acted upon — has made a significant conceptual and methodologic contribution toward resolving this dilemma (see O'Connor, 1993, 1995).

Conclusion

This paper has attempted to provide an overview of methodologic work investigating patients' treatment preferences. A notable proportion of this body of work has been undertaken by Canadian scientists with nursing backgrounds, who have paid particular attention to the conceptualization, development, and application of one emerging approach to quantifying patients' relative treatment preferences. The approach is highly adaptable — provided that the relevant probabilistic information is readily available or can be estimated with some confidence — and therefore highly context-dependent. It can be structured to illustrate in a highly graphic way the actual complex dilemmas patients often face, and its procedures can be arranged so as to engage the patient in explicitly considering the trade-offs involved. Given these visual and interactive characteristics, it seems to be a particularly promising way to help patients who wish to engage in this process to comprehend important probabilistic information and then use that information to clarify and communicate their values. The future phases of this cumulative work will be devoted to testing hypotheses that the probability trade-off technique actually can fulfil this function.

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Correspondence and reprint requests should be addressed to Dr. H.A. Llewellyn-Thomas, Clinical Epidemiology Unit, Sunnybrook Health Science Centre, G106, 2075 Bayview Avenue, North York, Ontario M4N 3M5 Canada. Telephone: (416) 480-6190; fax: (416) 480-6881; e-mail: hlt@ices.on.ca

Designer's Corner

"Decision-Making in Context": A Proposal for a Comprehensive Methodology

Franco A. Carnevale

Decision-making has been the focus of a significant number of studies in nursing as well as in the social sciences. These have included studies of coping, clinical judgement, and the management of ethical dilemmas, among many other topics. Studies of decision-making have relied largely on self-report methods such as interviews and paper-and-pencil tools. I shall outline some of the fundamental limitations of these approaches and propose a shift toward a contextual study of decision-making.

Use of self-report can be a valid way of accessing a person's (conscious) thoughts, preoccupations, preferences, and opinions. Following "the fall of behaviourism," such methods are a *necessary* component of most studies of human experiences. Informants' articulations are inescapable sources of insight in the quest to understand lived phenomena. However, self-report methods are *insufficient* for studies that are intended to examine phenomena comprehensively.

Self-report methods are highly problematic when used in studies, such as those of decision-making, that seek to draw inferences beyond the conscious thoughts, preoccupations, preferences, and opinions of individuals. Decision-making is a human practice — something a person does. A self-report study of a practice (such as decision-making, parenting, coping, relating, or grieving) presumes that the informant is conscious of its content and process and that there is a correspondence between what people do and what they say they do. There is reason to suspect that informants may misrepresent actual practices and respond in socially desirable ways.

Franco A. Carnevale, R.N., Ph.D., is Assistant Professor, School of Nursing, McGill University, Montreal, and Head Nurse, Pediatric Intensive Care Unit, Montreal Children's Hospital.

However, the inadequacy of self-report is not the result of informant misrepresentation. The principal problem is exclusive reliance on self-report, which is a result of the researcher's presumption that persons are consciously aware of what they do and are able to explain how and why they do it.

The Limits of Self-Report

To illustrate the limits of self-report, I shall draw on two examples.

In a recent study (Carnevale, 1997) carried out in a pediatric intensive-care unit, I examined life-support decisions among parents, physicians, and nurses who faced a number of ethical dilemmas requiring decision-making. Typically, the informants described decision-making in terms of deciding what was best for the child — striving to reconcile the value of the child's life with the quality of that life. My field observations highlighted additional, highly significant phenomena surrounding their decision-making process. Although the prevailing issue was framed as a (ethical) decisional dilemma, the process sometimes involved struggles among the informants. Each person overtly expressed what he or she thought was best for the child, yet their actions appeared to also express additional concerns, such as (1) their sense of duty toward the child, or (2) having their views respected by the other people involved in the child's life. When I shared my observations with the informants, they confirmed that they had these concerns. My field observations were crucial in illustrating that life-support decisions do not consist of a simple analytical calculus. They involve enactments within a complex social context. (For an elaboration of the relationship between sociocultural context and ethical decision-making, see Carnevale, 1996.)

This last point is congruent with the findings of a decision-making discourse analysis conducted in the United Kingdom. David Silverman (1987) examined videotapes of physician-parent interactions in a pediatric cardiology unit. The investigator was struck by the very low rates of cardiovascular surgery performed on children with Down's syndrome, compared to non-Down's syndrome children who had the same heart anomaly. In conformity with the prevailing practice of informed consent, parents were the ultimate decision-makers on record. They accepted or refused surgery based on what they thought was best for the child. However, the study's discourse analyses suggest that contextual phenomena significantly influenced the decisional process in a manner that the participants were unaware of.

It was the policy of the unit in which this study was conducted to discourage heart surgery on children with Down's syndrome. However, parents were not informed of this policy. They were informed of the surgical options — but in a manner that differed fundamentally from that in which parents of non-Down's syndrome children were informed. These latter parents were presented with a medical plan that explicitly stated the child required heart surgery. In contrast, parents of children with Down's syndrome were addressed in a manner that was medically less coercive and that focused to a greater degree on the child's social life. Physicians tended to view the Down's syndrome children as apparently enjoying life as they were. They stated that it was ultimately the parent's decision whether the child would undergo surgery; however, they added that they would not opt for surgery if the child were their own. Thus the decision-making of these parents was shaped by contextual phenomena of which they were unaware.

Toward a Contextual Construal of Decision-Making

I stress that I am not criticizing self-report methods per se. Rather, I am outlining a problem that resides in what the researcher does with these reports.

Self-report is a highly valuable means of understanding how things matter to a person. As Charles Taylor (1985) points out, a person self-interprets, elaborates his or her very particular understanding of a situation against a sociocultural horizon of significances. The person's own report is inescapably the most valid way of accessing this dimension of his or her experience.

However, nursing is a practice discipline. As such, it seeks to elaborate a body of knowledge that enables its practitioners to (1) interpret and understand human experiences and practices, and (2) foster favourable changes through clinical intervention. To this end, researchers strive to understand not only how things matter to persons, but also what these persons do, and why. Nurses are concerned with a person's thoughts and feelings — but they are also concerned with the person's practices, and the conditions that shape these thoughts, feelings, and practices. It is a mistake for a researcher to infer interpretations about the latter from self-reports about the former. Human practices such as decision-making cannot be adequately understood without systematically studying the context of such practices.

Pierre Bourdieu (1977, 1980), in his extensive studies of human practices, found that practice involves the expression of socially

acquired embodied mastery enacted within a complex process of improvisation.

The explanation agents may provide of their own practice, conceals, even from their own eyes, the true nature of their practical mastery, i.e. that it is learned ignorance... It follows that this learned ignorance can only give rise to the misleading discourse of a speaker himself misled, ignorant both of the objective truth about his practical mastery... and of the true principle of the knowledge his practical mastery contains. (Bourdieu, 1977, p. 19)

A comprehensive study of decision-making requires an integration of field-observation methods and self-report methods. The researcher engaging in such an integrated study would likely identify multiple phenomena that converge between these two methods and multiple phenomena that diverge. These should inform how the study is conducted as well as how its findings are analysed. Ethnography offers a cohesive research framework that could serve as an example of the integration of methods I am advocating.

Decision-making is a contextually grounded practice. Any full and rich understanding of this practice requires the use of contextual methods that construe it as "decision-making in context."

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Italo-Canadian Mothers' Beliefs Surrounding Cause and Treatment/Cure of Childhood Disabilities

Tracy Carr, Patricia McKeever, and May Yoshida

Une grille qualitative a été utilisée pour explorer les croyances italo-canadiennes, imprégnant la perception des causes, des traitements, et de la guérison d'invalidités infantiles. Un échantillon de commodité a été constitué avec la collaboration d'un centre de réhabilitation pédiatrique, situé dans le sud de l'Ontario. L'échantillon était composé de huit mères italo-canadiennes de deuxième génération, qui avaient des enfants atteints d'handicaps variant de moyens à graves. Des entrevues ont été menées auprès des mères, utilisant des questions ouvertes destinées à stimuler leurs réflexions et leurs émotions. L'analyse des données était faite en concomitance à la cueillette et consistait à effectuer une analyse de contenu. Trois catégories majeures de croyances traditionnelles en rapport à la cause ont été identifiées : (a) une punition pour des actes répréhensibles commis dans le passé; (b) un «mauvais sang» causé par les mariages entre membres d'une même famille ou une malédiction familiale; et (c) des forces surnaturelles, telles que le mal'occhio (le mauvais oeil). La catégorie de traitement majeure identifiée pour soigner les invalidités infantiles était la guérison par un processus magico-religieux. Selon les mères, ces croyances traditionnelles étaient plus fortes chez les Italo-Canadiens de première génération, notamment chez les grands-parents. Les mères exprimaient elles-mêmes leur adhésion à certaines de ces croyances, tout en acceptant très peu ou en rejetant certaines autres. À partir de cette étude, la formulation d'implications pouvant servir à la pratique serait prématurée. Toutefois, plusieurs voies de recherche à poursuivre ont été identifiées.

A qualitative design was used to explore Italo-Canadian beliefs about the cause and treatment/cure of childhood disabilities. A convenience sample of eight second-generation Italo-Canadian mothers of children with moderate to severe disabilities was recruited through a pediatric rehabilitation centre in Southern Ontario. The mothers were interviewed using open-ended questions that served as probes to stimulate their thoughts and feelings. Data analysis proceeded concomitantly with data collection, and consisted of content analysis. Three major categories of traditional causation beliefs were identified: (a) punishment for past wrongdoing, (b) "bad blood" caused by intermarriage or a family curse, and (c) supernatural forces such as *mal'occhio* (the evil eye). The major category identified for cure of childhood disability was magico-religious healing. These traditional

Tracy Carr, B.N.R.N., M.Sc., was, at the time of this study, a Master of Science student in the Faculty of Nursing, University of Toronto. She is now assistant professor, Department of Nursing, University of New Brunswick, Saint John. Patricia McKeever, Ph.D., R.N., is associate professor, Faculty of Nursing, University of Toronto, Ontario. May Yoshida, B.Sc.N., M.N., is professor, Faculty of Nursing, University of Toronto (now retired).

beliefs were described by the mothers to be strongest among first-generation Italo-Canadians, especially grandparents. The mothers themselves expressed their acceptance of some of these beliefs, but only minimal acceptance of or resistance to others. Based on this study, it would be premature to formulate implications for practice; however, several directions for future research are identified.

The ability of nurses to provide care that is culturally sensitive relates to the quality of the information available to them on how various groups experience and manage illness and disability. Although considerable knowledge has been accumulated about certain groups, surprisingly little is known about others. For example, Italo-Canadians have a strong numerical and historical presence in Canada, yet their beliefs and practices — especially those of Italo-Canadian women — have not been documented. To begin to address this gap in knowledge, we studied the beliefs and practices of Italo-Canadian mothers related to raising children with disabilities. These mothers constituted a sample in a larger study conducted by McKeever (1994).

Literature Review

A search of the literature found no research studies into Italo-Canadians' views of disabilities or their management of related experiences. However, the findings of studies with other ethnic groups reveal that the meaning and experience of illness and disability vary cross-culturally. The following are among the various explanations offered for illness and disability in both children and adults: (a) punishment from God for past sins on the part of parents, other family members, or ancestors (Chan, 1976; Groce & Zola, 1993; Lloyd, Jones, Yoshida, & Feldman, 1992); (b) supernatural forces (Cheon-Klessig, Camilleri, McElmurry, & Ohlson, 1988; Groce & Zola; Lloyd et al.; Mikhail, 1994; Plawecki, Sanchez, & Plawecki, 1994); (c) "bad blood" — disorders are thought to be inherited through intermarriage or a curse (Groce & Zola); (d) sins or wrongdoing in a previous life (Groce & Zola); (e) bodily imbalances caused by changes in body temperature or natural factors such as air and food (Groce & Zola; Mikhail); and (f) biomedical forces (Ahmann, 1994). It is important that we understand these explanations, because they influence how families and communities respond to disabilities in children and how they relate to the children and their parents (Caulcrick, 1980; Groce & Zola). However, such information should be used with caution, because culture alone cannot explain why individuals think and act as they do (Ahmann).

Several of the studies cited above (Cheon-Klessig et al., 1988; Groce & Zola, 1993; Lloyd et al., 1992; Mikhail, 1994; Plawecki et al., 1994) found that groups that retain traditional etiologic beliefs also tend to believe in traditional cures. These can include: (a) herbal and nutritional remedies, (b) religious healing, (c) sorcery/witchcraft, (d) ritualistic healing, (e) massage, (f) poultices, and (g) folk healing. Experts in traditional healing, usually elderly women (Bushy, 1992; Cheon-Klessig et al.), are often approached first, modern medicine being the avenue of last resort (Cheon-Klessig et al.; Germain, 1992; Gordon, 1994; Groce & Zola; Mikhail). Consequently, the investigators caution health professionals against giving their patients the impression that traditional healing practices are inferior to modern medicine. When traditional practices are depreciated, the researchers add, health advice and prescribed treatments are often rejected, and "non-compliant" behaviours can be the result (Bushy; Engebretson, 1994; Plawecki et al.).

These findings suggest that cultural values can greatly influence the perception and management of illness and disability. Inattention to this fact on the part of health professionals can alienate patients, and thus negatively affect their compliance with treatment plans.

We found no research describing the cultural beliefs and practices of Italo-Canadians surrounding illness and disability, yet some understanding of such beliefs and practices can help provide culturally acceptable health care to this population. The purpose of this study was, therefore, to explore Italo-Canadian beliefs about the cause and cure of childhood disabilities.

Research Questions

Four research questions guided the study. This report will focus on the findings generated by one of the questions: What are Italo-Canadian mothers' beliefs about causes and treatments/cures of their children's disabilities?

Method

Ethical approval was obtained, and participants were accessed through an urban pediatric rehabilitation centre in Southern Ontario. Once consent had been obtained, each mother was interviewed once, in her home, for about one hour. Follow-up telephone interviews were conducted with four mothers to confirm initial findings and to obtain additional data. One mother telephoned the interviewer twice to share new information. The follow-up telephone interviews served as a validity

check for the findings; the interviewees evaluated the findings for congruence with their own experiences. The interviews continued until no further data or insights were forthcoming from the informants. All interviews were audiotaped.

To stimulate thoughts and feelings, the following open-ended questions were used during the interview:

What do you understand ____'s problem to be? What concerns do you have for your child? In your culture/ethnic group, how is ____'s problem viewed? Are there special ways in which you and your family take care of ____? Have you looked for help for ____ from people other than health professionals? Tell me about a typical 24-hour day for you. What is family life like for you?

Not all questions were asked of each respondent; in some cases, one or two questions were enough to elicit substantive details. Observations about the mother, the child, and the environment were recorded after each interview.

Data analysis proceeded concomitantly with data collection. Segments of data comprising meaning units were identified and categorized according to a system of topical categories that had been derived from the research questions. Many topical categories also emerged from the data through on-going inductive analysis in which patterns or themes were identified and tagged. As categories were identified and refined, patterns and relationships within and between them became apparent. These were tested against the data through a process of searching for positive and negative instances of the pattern (Marshall & Rossman, 1989), using *The Ethnograph* computer program.

Results

Demographic Characteristics and Socio-economic Circumstances

The sample consisted of eight women between the ages of 26 and 43 years, with a mean age of 36. A relatively small sample of mothers was recruited because cultural knowledge is group-shared knowledge, and interviews on a topic with only a small number of respondents from a selected segment are required to identify shared cultural knowledge (Evaneshko & Kay, 1982; Schatzman & Strauss, 1973).

Of the eight women, five were second-generation Canadian, while three had immigrated to Canada from Italy before the age of 13. Like the majority of Italian immigrants to Canada, all had come from rural southern Italy, along with their parents and their husbands, after the

Second World War (Iacovetta, 1992). Most came from a background of subsistence farming, in which periodic hunger and famine were not uncommon.

Seven women were married and living with the father of the child with a disability, while one was a single mother who had been married and divorced twice. Although Italian was their mother tongue, all spoke fluent English as well. All the women had been raised Roman Catholic but one had become a Muslim and another a Jehovah's Witness, both as adults. They all lived in Italo-Canadian communities.

The children with disabilities ranged in age from two to 13 years, with a mean age of seven. They had at least one and at most three healthy siblings. Their disabilities — moderate to severe non-degenerative conditions in which neither cure nor death were imminent — were: severe asthma (1), spina bifida (4), cerebral palsy (5), and a rare neurological syndrome (1).

Beliefs About Causes and Treatments/Cures

All the mothers expressed an acceptance of modern medical explanations for their children's disabilities, and reported that they routinely sought and complied with prescribed treatments. This acceptance may reflect a sampling bias, because the mothers were recruited from a rehabilitation centre founded upon the notions of scientific medicine. The traditional Italian beliefs reported below were described by the mothers to be strongest among first-generation Italo-Canadians, especially grandparents. The mothers themselves expressed tolerance of some of these beliefs, but only minimal acceptance of or resistance to others.

Causes. All mothers viewed God as the ultimate power in causing and curing illness and disabilities. The most common belief was found to be that God "brought these children into the world" to teach the parents a lesson or to punish them for their sins. For example, one mother stated that if a person makes fun of or fails "to pity someone" who is disabled or disadvantaged God may punish that person with the same affliction (B-1482). A belief in retribution can result in blaming the parents, especially the mother, for the disability: "They have to pin-point; they have to blame somebody. They have to see evidence of blaming somebody ... and the ultimate is, 'What did you do? Maybe God is upset with you?' ... It's always, 'Oh there has to be a reason'" (K-1120). While three mothers expressed self-blame for their child's disability, five denied that they blamed themselves or accepted any blame placed on them by extended family members.

The mothers also reported the belief that illnesses and disabilities can result from “bad blood” introduced into families through intermarriage. This theory is sometimes used to blame in-laws for the child’s disability: “What they [the respondent’s parents] were saying was that these defective genes came from intermarrying between families... they said, ‘It wasn’t me. It must have been his parents’” (K-1111).

Finally, seven respondents reported that supernatural forces — such as sorcery, witchcraft, *mal’occhio* (the evil eye), or superstitions — might have caused their child’s disability.

Treatment/Cures. All categories of causes were considered to be subject to God’s will; therefore, disabilities were believed to be preventable and/or curable through magico-religious healing practices designed to please God or the saints. For example, the majority of the eight mothers explained that their parents often made vows or performed rituals in honour of the Madonna or a favourite saint, hoping their prayers would be answered with a miraculous cure. Yet they were fatalistic, believing that, regardless of their vows, God alone could bestow a cure or a miracle. A comment from one mother will serve to illustrate:

My mother-in-law is very religious. She believes that God will provide miracles if you pray hard enough. She takes Anna’s picture to Saint Anne, which is a Catholic church in Montreal where miracles happen. She does this once a year. She hopes that this might heal Anna. She always brings her back holy water and leaves it in our fridge and gets Anna to drink it... she just does these things because she thinks it is something she should do. She has made a commitment to Anna to do these things. If a miracle happens, it happens. God has the ultimate control, and is the only one who can change the way things are. (B-1501)

As intimated in the above quote, the mothers expressed neither total acceptance nor total rejection of a belief in miraculous cures.

The mothers considered first-generation Italo-Canadian women experts in magico-religious healing. These older women maintained a close relationship with the Roman Catholic Church, yet many engaged in officially forbidden healing practices. To protect newborn infants from *mal’occhio*, for example, they adorned them with gold necklaces and bracelets, pinned gold ornaments on their clothing, or sewed good luck charms into their underclothing. When children were born with abnormalities, the women prayed or made incantations while burning oil and wax. They also prepared traditional herbal potions. The mothers

described some of the healing rituals of their own first-generation mothers:

They have this thing — sometimes they light a candle, and they have this dish. They put oil in it to ward off the evil eye. (J-1258)

They have rituals. You know, if you do the rosary, like, a hundred times, or whatever, and you use it, your wish will come true. (F-1510)

Seven respondents explained that their parents, especially their mothers or mothers-in-law, encouraged them to engage in rituals and prayers to cure their children. Most mothers reported that they usually went along with these rituals but did not believe in them as strongly as their parents did.

Discussion and Implications

This study explored the beliefs of Italo-Canadian mothers surrounding the cause and the cure of their children's disabilities. Three major categories of traditional explanations for the disabilities were identified: (a) punishment for past sins, (b) "bad blood" due to intermarriage or a family curse, and (c) supernatural forces such as *mal'occhio*. The major category for cure of childhood disability was found to be magico-religious healing, including prayer, herbal potions, rituals, and sorcery/witchcraft. Variations of all of these categories have been identified in studies with Asian, North American Indian, and Hispanic cultures (Chan, 1976; Cheon-Klessig et al., 1988; Groce & Zola, 1993; Lloyd et al., 1992; Mikhail, 1994; Plawecki et al., 1994).

Traditional beliefs affected how the mothers were viewed by other family members — namely, blamed for the disability. This finding supports those of other studies that beliefs about causes of disability can influence how families and communities respond to disabilities in children and how they relate to the children and their parents (Caulcrick, 1980; Groce & Zola, 1993).

The traditional Italo-Canadian magico-religious healing rituals reported in this study were categorized as such because they were all intended to please God or the saints. The practices included: making vows or performing rituals to honour the Madonna or favourite saints, using traditional herbal medicine, and adorning the children to ward off evil. These practices were considered harmless by the mothers, and they sometimes instilled in them a sense of hope or spirituality even though they did not effect a cure. Leininger (1991) believes such traditional healing practices should be accepted and accommodated by nurses who care for people from different cultural groups, in order to

establish a mutually satisfying and trusting relationship with their clients.

The finding that traditional healing rituals were performed by many grandmothers, and were generally accepted by the mothers, supports the findings of other studies that experts in traditional healing are generally elderly members of the family or the community, and that younger people seek their advice (Bushy, 1992; Cheon-Klessig et al., 1988). Another finding that supports those of studies with other cultural groups is that traditional healing is used in combination with modern medicine (Cheon-Klessig et al.; Germain, 1992; Gordon, 1994; Groce & Zola, 1993; Mikhail, 1994). However, this study, unlike others reported in the literature, found that mothers routinely accessed modern medical services rather than viewing them as a last resort. This finding may be a reflection of the fact that the majority of respondents were second-generation Italo-Canadians, whereas traditional values are usually strongest among first-generation immigrants (Isajiw, 1975).

The findings of this study are inconclusive and should not be used to develop stereotypical approaches to treating Italo-Canadian families. It would therefore be premature to conclude that they have implications for nursing practice. However, several areas for future nursing research can be identified. To more fully understand Italo-Canadian experiences in mothering children with disabilities, research could be focused in the following areas: (a) beliefs about cause and cure of disability and illness, (b) the social and material circumstances of Italo-Canadian families, (c) Italo-Canadian experiences with the health-care system, and (d) Italo-Canadian attitudes toward disabled children, including the social roles that are deemed appropriate for disabled or chronically ill children. These areas for research would be amenable to both qualitative and quantitative approaches, depending on the nature of the research question. A qualitative approach similar to the one used in this study might be enhanced by the inclusion of a larger sample size, multiple interviews, and a comparative sample.

Continued research in these directions will help nurses and other health professionals provide competent and culturally meaningful care to Italo-Canadian families of children with disabilities. However, such accumulated knowledge should not be considered static or universally applicable to all Italo-Canadians: cultural beliefs, practices, and experiences can vary greatly among the various members of an ethnic group, as well as across time, space, generations, and socio-economic and political circumstances.

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Correspondence concerning this article should be addressed to Tracy Carr, B.N.R.N., M.Sc., Assistant Professor, Department of Nursing, University of New Brunswick, P.O. Box 5050, Saint John, New Brunswick E2L 4L5 Canada. E-mail: tcarr@unbsj.ca

Étude du lien entre le leadership transformationnel du personnel infirmier-chef et l'effort supplémentaire du personnel soignant

Gérard Ouimet et Louise Tourigny

The present study proposes to show that the ethos of the Head Nursing staff is related to the practice of transformational leadership, and to additional efforts displayed by the treatment staff. Using a sampling of 57 nurses, it was established that transformational leadership presented a positive influence on additional efforts which were superior to that produced by transactional leadership. Contrary to transactional leadership, transformational leadership was shown to exert a positive effect on the ethos of the leader who in turn, had a positive influence on the extra care supplied by the nursing staff.

La présente étude vise à démontrer que l'éthos du personnel infirmier-chef est relié à la pratique du leadership transformationnel et à l'effort supplémentaire déployé par le personnel soignant. À l'aide d'un échantillon de 57 infirmières et infirmiers soignants, il fut établi que le leadership transformationnel présente une influence positive sur l'effort supplémentaire supérieure à celle du leadership transactionnel et que, contrairement au leadership transactionnel, le leadership transformationnel exerce un effet positif sur l'éthos de la ou du leader qui, lui, influence à son tour, de manière positive, l'effort supplémentaire du personnel infirmier soignant.

Introduction

Le secteur de la santé fait l'objet d'énormes compressions budgétaires. Désormais, l'État ne se contente plus de fermer des lits d'hôpitaux mais procède également à la fermeture d'hôpitaux. Le défi d'une telle rationalisation exige que tout le personnel des centres hospitaliers soit mis à contribution. Étant des acteurs centraux au bon fonctionnement de tout hôpital, les membres du personnel infirmier-chef voient leur rôle de leader investi de nouvelles responsabilités. Les leaders ne peuvent plus se contenter d'être efficaces dans le processus d'échange transactionnel (contribution-rétribution), mais elles ou ils se doivent maintenant d'être transformationnels, c'est-à-dire provoquer chez le personnel soignant de profonds changements sur le plan de leurs perceptions et de leurs

Gérard Ouimet, Ph.D., est professeur agrégé de Psychologie organisationnelle et de Management, Service DGO, à l'École des Hautes Études Commerciales. Louise Tourigny, M.Sc., est étudiante au programme de doctorat conjoint en Administration à l'Université Concordia.

processus cognitifs se traduisant par une élévation des besoins de réalisation de soi. Une telle quête de réalisation de soi oblige le personnel soignant à rompre avec la routine et à déployer des efforts supplémentaires.

Sur le plan conceptuel, Dunham et Klafehn (1990) et McDaniel et Wolf (1992) ont établi que le personnel infirmier dirigeant, recourant au leadership transformationnel, peut inciter les infirmières et les infirmiers soignants à déployer plus d'efforts que ce qui est attendu d'eux par l'institution. Par ailleurs, se situant au coeur de notre problématique, Weatherly (1991) souligne l'existence d'une crise de leadership chez le personnel infirmier. Selon l'auteure, les comportements et les problèmes de communication du personnel infirmier dirigeant nuisent à l'engagement du personnel soignant. Or, Posner et Kouzes (1988) soulignent que l'*ethos* de la ou du leader, c'est-à-dire son honnêteté, son intégrité et la véracité de ses propos, sert de fondement à l'exercice de son influence. Par conséquent, la présente étude tentera de démontrer que l'*ethos* est relié à la pratique du leadership transformationnel du personnel infirmier-chef et qu'il peut influencer l'effort supplémentaire déployé par le personnel soignant.

Définition des principaux concepts

Bass (1985) est parvenu à distinguer deux styles de leadership qui, bien que distincts, n'en sont pas pour autant mutuellement exclusifs. Il s'agit du leadership transactionnel et du leadership transformationnel.

Le leadership transactionnel est un processus d'influence instrumental s'appliquant à la réalisation des activités journalières du personnel. Il est constitué de deux dimensions : le rôle de soutien axé sur la récompense et la gestion par exceptions. Le rôle de soutien axé sur la récompense consiste en la distribution de récompenses en fonction de l'atteinte des objectifs fixés. Dans la mesure où le personnel infirmier soignant satisfait les objectifs fixés en matière de rendement, la ou le leader lui consent une assez grande latitude dans l'exercice de ses fonctions. Une telle marge de manoeuvre constitue la gestion par exceptions. Toutefois, lorsque la situation l'exige, la ou le leader n'hésite pas à recourir à des renforcements positifs ou négatifs et à des punitions.

Cependant, le leadership transactionnel se veut dysfonctionnel dans une perspective, soit à long terme, soit de dépassement de soi et ce, faute de pouvoir provoquer chez le personnel infirmier soignant des changements au niveau de leurs valeurs et croyances. Seul le leadership transformationnel est ici en mesure de provoquer des changements

d'ordre supérieur. Selon Bass (1985), le leadership transformationnel est composé des dimensions suivantes : le charisme, la stimulation intellectuelle et la considération individuelle.

Le charisme consiste en la réaction d'identification et d'émulation du personnel infirmier soignant face au comportement de leur leader. La ou le leader charismatique présente une vision de façon claire et articulée et fait en sorte que le personnel infirmier soignant participe activement à la réalisation de cette vision. Le rôle inspirateur, composante du charisme, se manifeste lorsque la ou le leader produit des symboles relatifs à la vision et a recours à l'appel émotif afin d'accroître la conscience du personnel infirmier soignant.

La stimulation intellectuelle renvoie essentiellement aux encouragements de la ou du leader à l'endroit du personnel soignant. La ou le leader invite les membres du personnel soignant à rompre avec le passé et à remettre en question les façons traditionnelles de faire les choses, ce qui contribue à développer la pensée critique des membres du personnel infirmier soignant à l'égard du bien fondé de leurs propres valeurs, croyances et anticipations, de même que de celles de la ou du leader et de l'institution.

La ou le leader fait preuve de considération individuelle lorsqu'elle ou il traite chaque membre du personnel soignant de façon différente mais équitable. Elle ou il reconnaît les besoins individuels et élève les perspectives de réalisations de ses membres.

Sur le plan conceptuel, Miller (1989) propose l'existence d'un lien important entre le charisme de la ou du leader et son *ethos*. Selon elle, les objectifs du personnel infirmier-chef, sa vision et sa façon de communiquer les objectifs de l'institution contribuent au développement de son *ethos*.

L'*ethos* est une variable attributionnelle, c'est-à-dire qu'elle consiste essentiellement en la perception qu'a l'infirmière ou l'infirmier soignant de l'infirmière ou l'infirmier-chef. L'*ethos* peut être évalué à l'aide des propos de la ou du leader. Selon McCroskey (1966), l'*ethos* perçu d'une locutrice ou d'un locuteur se compose de deux dimensions : l'autorité et le caractère. L'autorité renvoie au niveau de compétence socialement reconnu de la locutrice ou du locuteur. La ou le leader possède de l'autorité lorsqu'elle ou il est reconnu expert dans son domaine, intelligent, informé, qualifié et fidèle. Le caractère fait référence au comportement et à la réputation de la locutrice ou du locuteur. Cette dimension de l'*ethos* de la ou du leader est élevée lorsqu'elle ou il est perçu plaisant,

amical, vertueux, sensible, honnête et dévoué par les membres du personnel soignant.

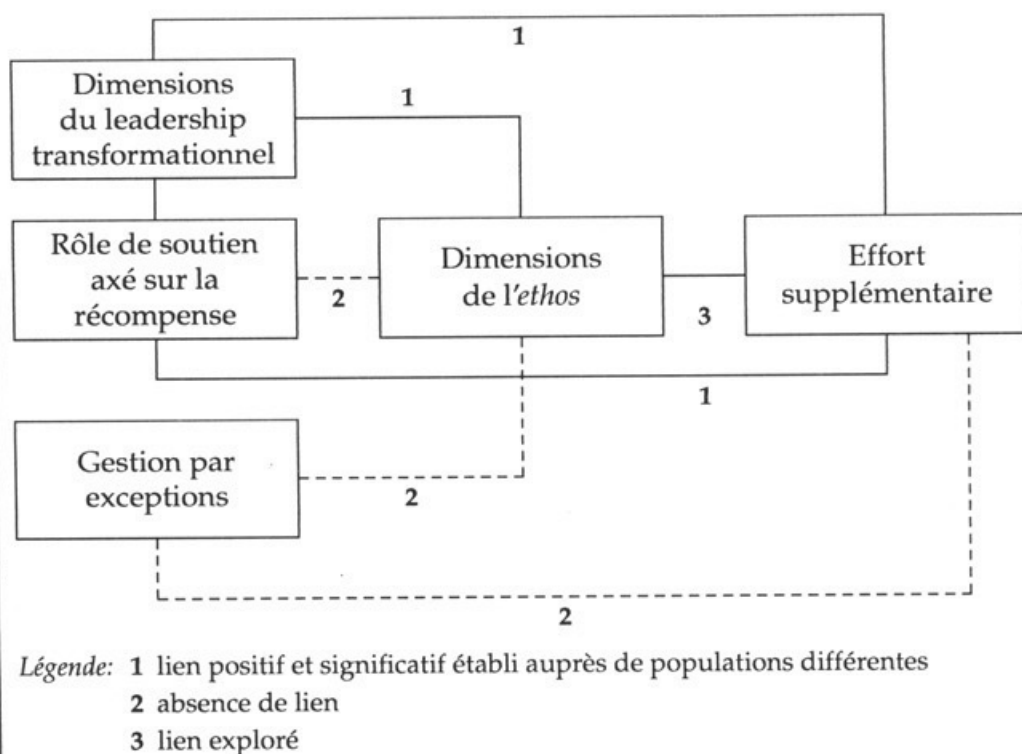
Objectifs de recherche et cadre d'analyse

Bass et Avolio (1990) ont effectué une synthèse de plusieurs études effectuées auprès de populations de gestionnaires occupant différents niveaux hiérarchiques et oeuvrant au sein d'entreprises manufacturières, industrielles et de haute technologie. Ils démontrent que le rôle de soutien axé sur la récompense a un effet positif sur l'effort supplémentaire. Par contre, comparativement au rôle de soutien axé sur la récompense, les dimensions du leadership transformationnel ont exercé une influence plus élevée sur l'effort supplémentaire. La gestion par exceptions n'a pas eu d'incidence sur l'effort supplémentaire. Dunham et Klafehn (1990) et McDaniel et Wolf (1992) ont constaté que les membres du personnel infirmier-chef étaient en majorité transformationnels. Cependant, elles n'ont pas établi de liens corrélatifs entre les dimensions du leadership et l'effort supplémentaire. Par conséquent, nous vérifierons l'existence des liens corrélatifs démontrés par Bass et Avolio (1990) à l'aide de données recueillies auprès du personnel infirmier soignant.

Podsakoff, Mackenzie, Moorman et Fetter (1990) ont recueilli des données auprès des membres du personnel oeuvrant dans l'industrie pétrochimique. Ils ont démontré que les dimensions du leadership transformationnel exercent une influence positive sur la confiance que les membres du personnel ont en leur leader. Par ailleurs, ils ont constaté que le rôle de soutien axé sur la récompense n'a aucun effet sur la confiance. Puisque sur le plan conceptuel, l'*ethos* constitue un antécédent de la confiance (Mayer, Davis et Schoorman, 1995), il nous est permis d'anticiper un lien positif entre les dimensions du leadership transformationnel et celles de l'*ethos*. Par contre, le rôle de soutien axé sur la récompense dépend beaucoup plus des politiques et des procédures de l'institution que de la volonté de l'infirmière ou l'infirmier-chef. Par conséquent, nous ne pouvons pas anticiper un lien positif entre cette dimension du leadership transactionnel et l'*ethos*. Enfin, Hater et Bass (1988), à l'aide des données recueillies auprès de gestionnaires oeuvrant au sein d'une entreprise spécialisée dans la livraison d'information et de biens, n'ont pas découvert de lien entre la gestion par exceptions et la persuasion (reliée à l'expertise de la ou du leader). La présente étude vérifiera les résultats obtenus au cours de ces recherches antérieures et tentera de démontrer que seules les dimen-

sions du leadership transformationnel exercent une influence positive sur l'*ethos*. Enfin, aucune étude n'a étudié l'existence d'un lien entre l'*ethos* et l'effort supplémentaire. Par conséquent, nous tenterons de démontrer que l'*ethos* exerce une influence positive sur l'effort supplémentaire. La figure 1 illustre les liens que notre étude tente de démontrer.

Figure 1 Illustration des liens analytiques



Méthodologie

Échantillon

Notre échantillon est composé d'infirmières et d'infirmiers professionnels anglophones et/ou bilingues d'un hôpital de la région de Montréal. Selon Simms (1991), les membres du personnel infirmier professionnel assument de grandes responsabilités en ce qui a trait aux soins des patients, utilisent des connaissances scientifiques et soulèvent des questions relatives aux pratiques des soins. Les infirmières et les infirmiers professionnels connaissent les lois, règlements, normes et règles d'éthique qui définissent l'étendue de leur pratique. Les membres du personnel infirmier professionnel doivent donc exercer

Bass (1985) a effectué une analyse factorielle avec composante principale et rotation de type varimax à l'aide d'un échantillon de 176 officières et officiers militaires. Les facteurs obtenus et leur pourcentage respectif de la variance expliquée sont présentés dans l'ordre : (1) le charisme (66 %), (2) le rôle de soutien axé sur la récompense (7,2 %), (3) la considération individuelle (6,3 %), (4) la stimulation intellectuelle (6,3 %) et (5) la gestion par exceptions (3,1 %). Le rôle inspirateur ne s'est pas comporté comme un facteur du leadership mais comme une composante du charisme.

L'*ethos* de la ou du leader fut mesuré à l'aide du questionnaire de McCroskey (1966). Rappelons ici que l'*ethos* est un antécédent de la confiance. Par conséquent, les questionnaires mesurant la confiance en les gens en général, en l'institution ou en une personne spécifique ne pouvaient donc pas être retenus pour les fins de notre étude. Parmi les mesures de l'*ethos*, le questionnaire de McCroskey (1966), présenté sous forme d'échelles sémantiques et différentielles, affiche des propriétés psychométriques très stables. Le test de consistance interne de Hoyt, utilisé à maintes reprises avec des données recueillies au moyen de cet instrument, a toujours produit des indices supérieurs à 0,90 et ce, tant pour l'autorité que pour le caractère.

L'effort supplémentaire fut mesuré à l'aide des trois questions suivantes : *Gets me to do more than I expected I could do*; *Motivates me to do more than I thought I could do* et *Heightens my motivation to succeed*. La validité de contenu réfère au nombre de questions sélectionnées de façon aléatoire afin de mesurer un concept. Une bonne sélection doit permettre de mesurer adéquatement tous les aspects d'un concept. Les trois questions satisfont ces exigences.

Résultats

Données relatives aux participant(e)s

Le nombre moyen d'années de service du personnel infirmier-chef de l'institution est de 13 ans et celui-ci varie entre une et 28 années. Le personnel infirmier-chef supervise en moyenne 35 infirmières et infirmiers soignants. Le nombre moyen d'années de service du personnel infirmier soignant au sein de l'institution est de huit ans. Ces données nous permettent de constater que les infirmières et infirmiers soignants connaissent en général leurs leaders depuis un nombre d'années suffisant pour pouvoir procéder à leur évaluation.

Tableau 1 <i>Constitution des indices des dimensions du leadership</i>		
Dimensions	Nombre de questions	Exemple de questions
Charisme	7	Has a sense of mission which he or she communicates to me
Stimulation intellectuelle	7	Requires that I back up my opinions with good reasoning
R�le inspirateur	5	Uses symbols and images to focus our efforts
Consid�ration individuelle	5	Gives personal attention to those who seem neglected
R�le de soutien ax� sur la r�compense	5	Sees that I get what I want in exchange for my cooperation
Gestion par exceptions	7	Focuses attention on irregularities, mistakes, exceptions, and deviations from what is expected of me

Propri t s psychom triques des instruments de mesure

Pour chacune des dimensions du leadership transformationnel et transactionnel, nous n'avons retenu que les  nonc s permettant d'obtenir la plus forte consistance interne afin de constituer les indices. Un indice est la moyenne des  nonc s mesurant une dimension pour chaque participante et participant. Le tableau 1 pr sente les dimensions du leadership, le nombre de questions utilis es afin de mesurer chacune de ces dimensions ainsi qu'un exemple de questions. Les coefficients alpha de Cronbach ont vari  de 0,76   0,95 pour les dimensions du leadership.

Une analyse factorielle avec composante principale et rotation de type varimax a  t  conduite avec les  chelles de McCroskey. Nous avons obtenu deux facteurs dont la valeur caract ristique exc dait 1 : l'autorit  et le caract re expliquant respectivement 57,2 % et 14,2 % de la variance totale. Les six questions relatives   l'autorit  ont pr sent  des coefficients de saturation plus grand que 0,70 avec ce facteur. Quatre des six  chelles mesurant le caract re pr sentent des liens tr s forts avec celui-ci (saturation de 0,65   0,90). Les deux autres  chelles ont pr sent  des liens avec les deux facteurs. Il s'agit de l'honn t t  et du d sint ressement qui se r f rent aux intentions du locuteur. Ces deux  chelles n'ont donc pas servi   la constitution des indices.

Les coefficients alpha sont de 0,93 pour l'autorité et de 0,87 pour le caractère.

Interprétation des résultats

Le tableau 2 présente la moyenne, l'écart-type et les coefficients alpha de Cronbach pour chacune des mesures ainsi que les corrélations entre les dimensions du leadership, celles de l'*ethos* et le concept de l'effort supplémentaire.

Tableau 2 *Matrice des corrélations*

	X	δ	Char	Cons	Insp	Stim	Soutien	Except	Effort	Auto	Carac
Char	2,42	1,28	0,950								
Cons	2,29	1,19	0,897**	0,883							
Insp	2,04	1,27	0,875**	0,885**	0,881						
Stim	2,25	1,21	0,659**	0,601**	0,608**	0,923					
Soutien	1,75	1,19	0,420**	0,404**	0,446**	0,463**	0,872				
Except	1,75	1,21	-0,035	-0,071	0,043	0,218	0,234	0,761			
Effort	1,98	1,34	0,709**	0,763**	0,759**	0,639**	0,521**	0,136	0,810		
Auto	3,00	1,03	0,707**	0,602**	0,550**	0,586**	0,142	0,099	0,371**	0,933	
Carac	2,99	0,80	0,795**	0,752**	0,723**	0,442**	0,333*	0,019	0,585**	0,577**	0,873

- Notes :
1. Courbe d'acceptation bi-caudale (2-tailed).
 2. Les coefficients alpha de Cronbach sont présentés sur la diagonale.
 3. Les coefficients de corrélations de plus de 0,33 sont significatifs $p < 0,05$.
 4. Les coefficients de corrélations de plus de 0,37 sont significatifs $p < 0,01$.
 5. Les abréviations correspondent dans l'ordre aux termes suivants : charisme, considération individuelle, rôle inspirateur, stimulation intellectuelle, rôle de soutien axé sur la récompense, gestion par exceptions, effort supplémentaire, autorité et caractère.
 6. Les abréviations X et δ correspondent à la moyenne et l'écart-type des mesures.

Les corrélations entre les dimensions du leadership transformationnel et l'effort supplémentaire sont très élevées ($0,639 \leq r \leq 0,763$; $p < 0,01$). La corrélation entre le rôle de soutien axé sur la récompense et l'effort supplémentaire ($r = 0,521$; $p < 0,01$) est moins élevée. La gestion par exceptions n'a cependant pas démontré de lien avec l'effort supplémentaire ($r = 0,136$; $p \geq 0,05$). Ceci confirme les résultats obtenus par Bass et Avolio (1990).

Les dimensions du leadership transformationnel ont présenté des corrélations positives et significatives avec les dimensions de l'*ethos* ($0,442 \leq r \leq 0,795$; $p < 0,01$). Contrairement à nos attentes, le rôle de soutien axé sur la récompense a présenté une corrélation positive et significative ($r = 0,333$; $p < 0,05$) avec le caractère. Ceci peut être expliqué par le fait que l'échange de récompenses influence la façon dont les membres du personnel infirmier soignant perçoivent la sensibilité de leur leader. Une ou un leader sensible peut percevoir les attentes de ses infirmières et infirmiers soignants et s'assure de faire en sorte qu'elles ou ils obtiennent une juste récompense en fonction de leur effort. Le rôle de soutien axé sur la récompense n'est pas lié à l'autorité et la gestion par exceptions ne présente aucun lien avec les dimensions de l'*ethos*. Ceci confirme donc partiellement les résultats obtenus lors des études antérieures (Hater et Bass 1988; Podsakoff, MacKenzie, Moorman et Fetter, 1990). Enfin, les corrélations entre les dimensions de l'*ethos* et l'effort supplémentaire démontrent qu'il existe un lien important entre ces deux concepts.

Il sied de spécifier que le coefficient de corrélation (r) indique la grandeur et la direction d'une relation linéaire. Cependant, il ne nous permet pas de prédire la valeur d'une variable dépendante en fonction d'une variable indépendante. Par conséquent, il convient de procéder à des régressions. Cependant, les très fortes corrélations obtenues soulèvent le problème potentiel de multicollinéarité. Afin de vérifier si nous étions en présence d'un tel problème, nous avons entré les dimensions du leadership transformationnel et transactionnel comme variables indépendantes dans une régression multiple où l'effort supplémentaire fut entré comme variable dépendante. La valeur VIF — la réciproque de la mesure de la tolérance — fut calculée pour chacun des facteurs ne pouvant être entrés dans l'équation parce que non significatifs ($p > 0,05$). Nous avons obtenu les résultats suivants : le rôle inspirateur ($\beta = 0,62$; $p < 0,01$) et la stimulation intellectuelle ($\beta = 0,25$; $p < 0,05$) ont tous deux exercé une influence significative sur l'effort supplémentaire ($r^2 = 0,64$ et $p = 0,0000$). La valeur VIF des facteurs rejetés varie entre 1,55 et 5,44, ce qui indique un problème de multicollinéarité. Par conséquent, nous avons effectué des régressions simples. Cependant, afin d'éviter l'erreur de type 1, nous ne devons tenir compte que des effets qui présentent un très haut niveau de signification $p < 0,01$. Les résultats des régressions simples sont présentés au tableau 3.

Le charisme, le rôle inspirateur et la considération individuelle expliquent une forte proportion de la variance de l'effort supplémentaire et du caractère ($0,53 \leq r^2 \leq 0,65$). Par contre, ils expliquent une plus faible proportion de la variance de l'autorité ($0,29 \leq r^2 \leq 0,49$).

L'autorité pourrait donc dépendre d'autres facteurs que nous n'avons pas contrôlés (ex. : formation antérieure, domaine d'expertise et nombre d'années d'expérience au sein de la profession).

Tableau 3 Régressions simples

	Variables dépendants								
	Effort supplémentaire			Autorité			Caractère		
	r ²	β	p	r ²	β	p	r ²	β	p
Charisme	0,53	0,73	0,0000	0,49	0,71	0,0000	0,65	0,81	0,0000
Rôle inspirateur	0,61	0,79	0,0000	0,29	0,55	0,0000	0,53	0,73	0,0000
Considération individuelle	0,58	0,76	0,0000	0,36	0,61	0,0000	0,56	0,76	0,0000
Stimulation intellectuelle	0,40	0,65	0,0000	0,33	0,58	0,0000	0,18	0,45	0,0000
Rôle de soutien axé sur la récompense	0,26	0,52	0,0001	0,00	0,14	0,3256	0,09	0,33	0,0182
Gestion par exceptions	0,01	0,16	0,2475	0,00	0,15	0,2753	0,02	0,02	0,9131
Autorité	0,13	0,39	0,0056						
Caractère	0,33	0,59	0,0000						

La stimulation intellectuelle n'explique que 40 % de la variance de l'effort supplémentaire. Par conséquent, bien que la remise en question des façons traditionnelles de faire les choses puisse favoriser le développement de l'esprit critique chez le personnel infirmier soignant, il est possible qu'une telle remise en question engendre de l'hésitation face aux décisions à prendre. De plus, la stimulation intellectuelle peut insécuriser les membres du personnel soignant ayant à faire face à une plus grande incertitude dans la pratique de leur profession.

La stimulation intellectuelle explique 33 % de la variance de l'autorité alors qu'elle n'explique que 18 % de la variance du caractère. À l'opposé, les autres dimensions du leadership transformationnel expliquent un plus fort pourcentage de la variance du caractère ($0,53 \leq r^2 \leq 0,65$) que de l'autorité ($0,29 \leq r^2 \leq 0,49$). Enfin, le caractère explique 33 % alors que l'autorité n'explique que 13 % de la variance de l'effort supplémentaire. Par conséquent, le rôle exercé par la stimulation

intellectuelle et l'autorité diffère de celui qui est exercé par les autres dimensions du leadership transformationnel et par le caractère. Il est possible que la stimulation intellectuelle et l'autorité exercent une influence plus importante à long terme qu'à court terme, alors que les autres dimensions ont un effet plus élevé à court terme sur l'effort supplémentaire. En effet, la remise en question des valeurs et des croyances n'est pas un processus dont les conséquences peuvent être évaluées à court terme.

Le rôle de soutien axé sur la récompense explique un faible pourcentage de la variance de l'effort supplémentaire et n'explique aucun pourcentage de la variance des dimensions de l'*ethos*. La gestion par exceptions n'explique aucun pourcentage de la variance de l'effort supplémentaire et des dimensions de l'*ethos*. Ces résultats confirment que seules les dimensions du leadership transformationnel peuvent expliquer un fort pourcentage de la variance des dimensions de l'*ethos*.

Discussion

Nos résultats sont en conformité avec les anticipations de Miller (1989) qui propose un lien important entre le charisme et l'*ethos* du personnel infirmier-chef. Ils confirment aussi les résultats de Posner et Kouzes (1988) qui ont découvert que l'honnêteté, l'intégrité et la véracité des propos de la ou du leader servent de fondement à l'exercice de son influence. Il appert que le caractère joue un rôle plus important que l'autorité dans l'engagement du personnel soignant. En effet, nos résultats démontrent que l'autorité, bien qu'importante dans le processus de remise en question des valeurs traditionnelles, exerce une moins grande influence sur l'effort supplémentaire. Cependant, il serait intéressant de procéder à une étude longitudinale afin d'évaluer l'influence à long terme de la stimulation intellectuelle et de l'autorité sur les valeurs et les croyances du personnel infirmier soignant. De plus, il serait important d'inclure des variables de contrôle (ex. : nombre d'années d'expérience) afin d'isoler le pourcentage respectif de variance expliquée par la stimulation intellectuelle et l'autorité.

Nos résultats confirment que les comportements et la véracité des propos du personnel infirmier-chef sont en relation directe avec l'effort que les infirmières et les infirmiers soignants sont prêts à déployer pour l'institution (Dunham et Klafehn, 1990; McDaniel et Wolf, 1992; Weatherly, 1991). Les recherches ultérieures pourraient inclure une mesure de l'engagement organisationnel afin de vérifier si les dimensions du leadership transformationnel exercent une influence importante sur l'engagement envers l'institution et si celui-ci exerce une

influence à court ou à long terme sur l'effort supplémentaire. De plus, d'autres facteurs (ex. : conjoncture économique) peuvent expliquer un certain pourcentage de la variance de l'effort supplémentaire. Par conséquent, nous devons tenter d'isoler l'influence respective des facteurs affectant l'engagement organisationnel et pouvant être contrôlés par le personnel infirmier-chef afin que ce dernier puisse exercer une influence directe sur le déploiement de l'effort supplémentaire.

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Insights from a Nursing Research Program on Social Support

Miriam J. Stewart, Mary Lou Ellerton, Geraldine Hart, Alexandra Hirth, Karen Mann, Donna Meagher-Stewart, Judith Ritchie, and Gail Tomblin-Murphy

Cet article met en lumière les implications conceptuelles et pratiques d'un programme de recherche en sciences infirmières, dont l'accent est mis sur le soutien social. Le cadre de travail conceptuel à la base du programme comporte les éléments suivant : les diverses dimensions du concept de soutien social; le lien au stress et à l'habileté d'adaptation; et les effets sur la santé. Ces associations feront l'objet de précisions à travers des exemples provenant de huit études d'évaluation et quatre études d'intervention. Le programme de recherche a généré de nouvelles connaissances et appuie les résultats déclarés d'autres recherches menées sur le thème du soutien social.

This paper highlights the conceptual and practical implications of a nursing research program that focuses on social support. The diverse dimensions of the construct of social support; its relationship to stress and coping; and its impact on health, health behaviour, and use of health services are explicated in the conceptual framework underpinning the program. These associations will be elucidated by citing examples from eight assessment studies and four intervention studies. The research program yielded new insights and reinforced reported findings of other social-support research.

Social support is a significant factor for nurses: it influences health status (House, Umberson, & Landis, 1988; Kaplan & Toshima, 1990), health behaviour (Bloom, 1990), and use of health services (Birkel & Repucci, 1983). Nurses have made significant contributions to the scrutiny, conceptualization, and measurement of social support and to its use in interventions; nursing interventions, in turn, can help mobilize and augment the social support that clients receive.

Conceptual and practical insights have emerged from a five-year nursing research program, the aims of which were as follows: to assess the social support received by diverse populations; to examine the conceptual links among social support, coping, and stress; and to test the impact of support interventions on health outcomes. Examples from eight assessment studies and four intervention studies (see Table 1)

Miriam J. Stewart, Ph.D., Mary Lou Ellerton, M.N., Geraldine Hart, M.N., Alexandra Hirth, M.N. (deceased), Karen Mann, Ph.D., Donna Meagher-Stewart, M.N., Judith Ritchie, Ph.D., and Gail Tomblin-Murphy, M.N., are with the Dalhousie University School of Nursing in Halifax.

Table 1 *Social Support Research Program: An Overview*

Support Domain	Assessment Project	Intervention Project
Support for persons with chronic illness and their family caregivers	Mothers of children with a chronic illness (N=90)	Telephone-support intervention for children with a chronic illness and their families (N=120)
	Children with a chronic illness (N=60) Children experiencing stressful health-care encounters (N=80)	<i>Computer peer support for children with chronic illness¹</i>
	Men with hemophilia and HIV / AIDS and their family caregivers (N=90)	Telephone-support groups for men with hemophilia and HIV / AIDS and their family caregivers (N=10)
	Persons with stroke (N=48) or heart failure (N=48) and their family caregivers	Peer home-visit support for caregivers of stroke survivors (N=30)
	Psychosocial factors associated with re-admission for IHD (N=100)	Fact-to-face support groups for couples coping with IHD (N=38)
Support for professional caregivers	Support, stress, job satisfaction, and coping among nurses in HIV / AIDS care, in community (N=63), hospital (N=114)	Support groups and mentors for community and hospital-based nurses HIV / AIDS care ² (N=100)
	Support, stress, and satisfaction experienced by community health nurses (N=101)	
Peer and professional support	Partnership of health professionals and members of self-help groups (N=96)	Education resources for health professionals ²

¹ Study proposal in development stage

² Available from Self-Help Canada

will be cited throughout, to illustrate sources, types, and appraisal of support; links between stress and social support and between coping and social support; and the effect of social support on health, health behaviour, and use of health services. Information about the methods and measures of these projects is available from the authors upon request.

Social support is defined here as *interactions with family members, friends, peers, and health professionals that communicate information, esteem, aid, or emotional help. When these communications are perceived as supportive, they may enhance coping, moderate the impact of stressors, and promote health* (Stewart, 1993). The multifaceted dimensions of the construct of social support — structure, function, and appraisal — were investigated as part of the research program.

Sources of Support

The *structure* of social support comprises lay sources such as partners/spouses, family members, friends, neighbours, co-workers, volunteers, and self-help groups, as well as professional sources. Professionals can provide intermittent specialized support and mobilize lay support (Norbeck, 1988).

The findings of the studies in our five-year program are consistent with those of other research on support providers (e.g., Dakof & Taylor, 1990) in that most support was provided by family members and/or within close relationships. Both mothers of children with a chronic illness (Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994) and persons with ischemic heart disease (IHD) (Stewart, Hirth, Klassen, Makrides, & Wolf, in press) indicated that most of their support came from spouse/partner, family members, and friends. Children with chronic conditions indicated that their key supporters were their parents and other family members. Sources of support for professional caregivers were found to be similar to those for lay caregivers, with one exception — professionals named co-workers more frequently. Canadian nurses working as HIV/AIDS caregivers gave their sources of support as spouses/partners, family members, friends, and *associates*.

The support provided by or sought from health professionals and peers emerged as a theme in several of the studies in the program. Some mothers of children with a chronic illness indicated that they perceived health professionals as providers of support, but others reported that they received inadequate support from health professionals. Ellerton, Ritchie, and Caty (1994) observed that young children actively

sought and received the support of nurses during venipuncture. In contrast, studies of stroke survivors, persons with cardiac disease, and men with hemophilia and HIV/AIDS found that health professionals were infrequently identified, by both the client and the family caregiver, as sources of support.

The studies revealed that the peer supporter and the recipient should be very closely matched, and they uncovered a preference for disease-specific peers in dyadic or group relationships. Men with AIDS and hemophilia sought support from identical peers — that is, men with AIDS and *hemophilia*, and not persons with AIDS from other causes (Stewart, Hart, & Mann, 1995). Mothers of young children with cystic fibrosis sought support groups comprising mothers of *young* children with *cystic fibrosis*, and not mothers of variously aged children with another chronic illness. The study of children with chronic conditions revealed that they received less peer support than their healthy counterparts.

The findings of these studies have implications for support interventions, particularly those involving both professionals and peers. Nursing interventions can be guided by respondents' preferences for peers who might provide affirmational support (involving feedback and appraisal). The assessment studies in the research program indicate that we must look more closely at certain personal and illness dimensions — such as cause of the illness, time elapsed since diagnosis, gender, age, marital status, and impact of the illness. The findings of the intervention studies with stroke survivors and hemophiliacs with HIV/AIDS and their family caregivers, and with couples coping with myocardial infarction (MI) reinforce the importance of peer matching.

Functions of Support

The functions of support are fourfold: emotional, instrumental (practical), informational, and affirmational. The function should be specific to the stressors encountered (Cutrona, 1990), and type and source of support should be matched (Dakof & Taylor, 1990). Mothers of children with a chronic condition reported that they received informational support from health professionals, but typically they did not receive needed feedback (affirmation support), understanding (emotional support), or reassurance. Hemophiliacs with HIV/AIDS and their family caregivers (who found it stressful to cope with uncertainty about the course of the illness and the treatment options) received informa-

tional support from professionals, but practical aid from relatives and emotional support primarily from spouses and members of the immediate family.

The investigation into the relationship between self-help groups and health professionals revealed that professionals act as consultants, educators, and referral resources (providers of informational support), while peers are valued for their emotional support and for their affirmational support based on first-hand experience with a stressor (experiential knowledge) (Stewart, Banks, Crossman, & Poel, 1994). The findings of this study are similar to those of the study with men who had hemophilia and HIV/AIDS: participants favoured an approach whereby mutual aid/support groups are led jointly by peers and professionals — an approach that acknowledges the importance of both professional and experiential knowledge. Therefore, the telephone-support groups for hemophiliacs with AIDS and their family caregivers and for parents of children with chronic illness, as well as the face-to-face-support groups for couples coping with MI, were co-facilitated by a peer and a professional. In the intervention studies, professionals provided mainly informational support, while peers offered affirmational and emotional support.

In many of the studies, a pattern of support specialization emerged across the groups of respondents: family members were perceived to specialize in practical support, health professionals in informational support, intimates (spouses/partners) in emotional support, and peers in affirmational support. However, spouses also provided other types of support. This suggests that support figures do not always substitute for one another, and that nurses might assess clients' and caregivers' unmet expectations for particular kinds of support from particular sources.

Appraisal of Support

As social support may be either perceived as available from the social network, or actually received (delivered) (Sarason, Sarason, & Pierce, 1990), it is important that we distinguish between the two (Dunkel-Schetter & Bennett, 1990). If support is to be appraised with respect to its direction and its benefits or drawbacks, nurses should assess clients' receipt of support as well as their perceptions of the kinds of support that are available.

Direction

Support can be either unidirectional/non-reciprocal or bidirectional/reciprocal; norms of equity and reciprocity (Tilden & Galyen, 1987) suggest that it should be bidirectional. Social exchange and equity theories indicate that social support can involve benefits and costs to both recipient and provider. Nevertheless the notion of reciprocity has largely been ignored in studies of social support (Winemiller, Mitchell, Sutcliffe, & Cline, 1993) — despite the fact that non-reciprocal relationships within their social networks diminish the self-esteem of people with illnesses and increase their sense of indebtedness (Simmons, 1994).

One study in our research program found that, as their illness progressed, stroke survivors and persons with severe heart disease were concerned about their inability to reciprocate spousal support, because of increasingly limited function and reduced ability to provide certain types of support. Gottlieb (1989) found that many caregivers of the chronically ill experienced lack of reciprocity. In contrast, the findings of two studies revealed that the family caregivers of men with hemophilia and AIDS and the mothers of children with a chronic illness did not express the negative feelings of burden typically associated with the unequal caregiver-recipient relationship. Perhaps the commitment to a long-term intimate relationship overshadowed the need for immediate reciprocity. This reflects the relatively recent notion of lifespan reciprocity (Antonucci & Jackson, 1990) and indicates that there might be several types of reciprocity, depending on the particular relationship. During the course of another study, reciprocity emerged as a key characteristic of partnership and of a relationship involving health professionals and members of self-help groups. The assumption that interventions involving peers typically promote reciprocity (Katz, 1993) informed the design of the telephone-support group interventions for hemophiliacs with AIDS and their family caregivers and for parents of children with a chronic illness. Reciprocity with peers and exchange of information and support were cited as key benefits of the face-to-face support groups for couples coping with MI and of the telephone-support groups for persons with HIV/AIDS.

Drawbacks

Network support can also have negative effects (Brenner, Norwell, & Limacher, 1989); indeed most social relationships feature both supportive and stressful elements (Rook, 1990), and ties with friends and families can be a source of stress and conflict. Drawbacks affect both provider and recipient. The provider might experience overload or

overexposure to chronic and acute stresses, or might be overly protective, committed, or emotionally involved. The recipient might experience diminished trust, loss of support, bad advice, learned helplessness, or relational costs (La Gaipa, 1990). Support might be perceived as unhelpful, particularly if it undermines the recipient's sense of self-esteem. The negative aspects of social networks have not been sufficiently researched, and measures of social support typically disregard the negative aspects of relationships.

Perceptions of low support can reflect the absence of a supportive relationship or the presence of a negative, *conflicted* relationship (Coyne & Bulger, 1990). Conflict and negative interactions correlate with low perceived support more strongly than do positive ones (Schuster, Kessler, & Aseltine, 1990). Negative relationships in our study of health professionals and members of self-help groups entailed conflict, power struggle, competitiveness, dominance, territoriality, and judgemental behaviour. Men with hemophilia and AIDS experienced prejudice and insensitivity from health professionals and avoidance by friends. Mothers of children with a chronic illness received conflicted support involving criticism or condescension from family and friends, but mostly on the part of health professionals, some of whom reportedly communicated information in a heartless fashion (Stewart et al., 1995).

Even successful relationships involve lapses in support, miscarried support (Sarason et al., 1990), and failed support modes or functions (Eckenrode & Gore, 1990). The mothers of children with a chronic illness were concerned less about conflict than about miscarried and *absent* support — anticipated support that did not materialize. One mother explained that her husband failed to "participate as much as I would like. I know if I asked him, he would. But I don't feel like I should ask him. I feel like he should volunteer." The mothers' descriptions of their partners' failure to enforce the child's treatment regimen and positive health behaviours represented *miscarried* support. The intervention studies found that men with AIDS and their family caregivers received inadequate information and attention from health professionals, while the caregivers of stroke survivors found it stressful to contend with *absent* support from family, friends, and health professionals.

Such drawbacks can have a more powerful influence on health (House et al., 1988; Rook, 1990) and use of health services than the more general benefits of support. Therefore, both the supportive and non-supportive features of clients' interactions and relationships should be assessed.

Duration of Support

Support will either endure or dissipate over time. Network changes (Bernard et al., 1990) and patterns of support in chronically stressful situations, such as illness or caregiving, have yet to be examined. The investigation of the role of social support in early re-admission to hospitals for cardiac disease found that persons who were re-admitted received less support from neighbours than persons who were not re-admitted. Mothers of children with a chronic illness indicated that support did not endure, and that when they needed support — at the time of diagnosis when they were overwhelmed by new caregiving demands — they did not receive it. As a result, our current telephone-support trial focuses on parents of chronically ill children under seven years of age.

These studies have implications for the timing of support interventions. One such intervention was directed at new family caregivers of persons who had experienced a severe stroke for the first time and had recently been discharged. The studies also have implications for the duration of support, which is important for determining intervention "dose" and stability of outcome. Reports of telephone-support interventions suggest that their typical six-week duration was inadequate (Gottlieb, 1991). One intervention study in our program involved a peer visiting the home of the new caregiver of a stroke survivor twice weekly over 12 weeks, with impact re-assessment after three and six months. In the delayed post-test interviews, caregivers said they missed the visits when they had been terminated. The telephone-support interventions for hemophiliacs with HIV/AIDS and their family caregivers also lasted 12 weeks — longer than most telephone-support interventions reported in the literature. Post-intervention interviews showed that both the affected men and their caregivers would have liked them to continue.

These findings indicate that in order to determine the needs of their clients, nurses should assess: types of support required or available for various stressors; sources of support; reciprocity of support; costs and benefits associated with support; satisfaction with support; behaviours perceived as supportive or non-supportive; underuse and overuse of support resources; and timing and duration of support. However, support is one of many factors that nurses must assess. A screening interview focusing on satisfaction with support and number and type of supporters could therefore be followed by a detailed assessment of the support needs of clients at risk (e.g., those who are lonely or isolated). Nurses could test the long-term impact of support interventions

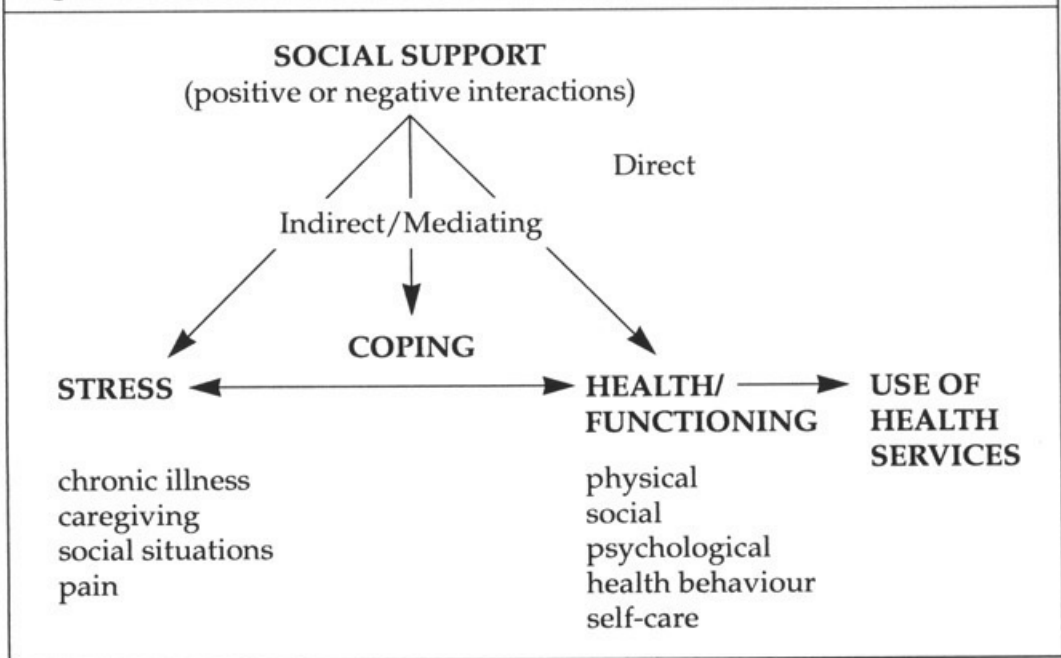
designed to lessen the impact of negative interactions and absent support.

Relationship between Stress and Social Support

Figure 1 represents the conceptual framework of the research program: the relationships between social support and stress, social support and coping, and social support and health. The two-way arrow indicates that the stress-social support relationship is reciprocal. The arrow from support to stress indicates that support can be stressful. Attribution, social exchange, and social comparison theories have been invoked to interpret miscarried or inadequate helping (Buunk & Hoorens, 1992). In our study with mothers of children with a chronic condition, conflict with their spouse over the child's care and absent anticipated support were perceived stressors. The investigation of the support needs of men with hemophilia and AIDS and their family caregivers revealed that insensitivity, prejudice, and avoidance on the part of friends and health professionals were particularly stressful. The children who had chronic illnesses identified peer relationships as a major everyday life stressor and restrictions that inhibited social activities and relationships as a major illness-related stressor.

Conversely, support can mediate or moderate the impact of stressful situations on health and functioning (Figure 1). This framework acknowledges that a stressful situation can be chronic or acute. Stress-moderating processes determine a person's reaction to or appraisal of stress (Eckenrode & Gore, 1990). Our study with persons with ischemic heart disease identified instructive differences involving stress appraisal and social support. Persons admitted for the first time appraised the stress associated with their condition as less central and threatening, and received less emotional and affirmational support from health professionals, than persons with multiple admissions for cardiac illness. The mothers of children with a chronic illness described specific types of support from specific sources with respect to specific stressors or caregiving burdens. In the investigation of resources influencing young children's coping with a stressful procedure, supportive nursing interventions were associated with reports of less pain. In a different context, support was related negatively to stress experienced by community health nurses. All intervention studies were based on the premise that support has a moderating effect on appraisals of stressfulness in chronic illness and caregiving. It is therefore predicted that the telephone-support groups for parents of children with a chronic condition will result in decreased parental perceived stress.

Figure 1 *Framework of Social Support Research Program*



Social Support and Coping

This research program recognizes the limitations of an individualistic perspective that ignores the social context of coping (Folkman et al., 1991). The way in which an individual copes is affected by others, irrespective of whether the person seeks support. The two-way arrow in Figure 1 suggests that the support-coping relationship is reciprocal.

Social support is conceptualized as a coping resource or a form of coping assistance (Thoits, 1986). The arrow from social support to coping indicates that supportive persons can affect appraisal, sustain coping efforts, and influence choice of coping strategies. Social support may also augment the coping resources that are available to deal with stressful encounters. Furthermore, receipt of support can change the trajectory of coping. Finally, perceived availability of social support has been linked to coping effectiveness (Bennett, 1993).

Conversely, the arrow from coping to support indicates that how a person copes can provide clues to potential supporters about whether support is needed and, if so, the types of support that are needed (Silver, Wortman, & Crofton, 1990). People who use avoidance and distancing strategies tend to have fewer support resources, while support-seeking has been linked to greater provision of support (Dunkel-Schetter & Skokan, 1990). Indeed, how one copes can influence the course of interpersonal interactions and the nature and quality of

support that will be received (Silver et al.). Thus social support influences coping abilities, while coping strategies influence the type of support that is sought and received.

Several studies in the program explored the links between coping and support. The study of children's support found that healthy children sought support from friends as a coping strategy more often — and had more supporters — than children with a chronic illness. The investigation of nurses in HIV/AIDS care revealed that the coping strategies "seeking support" and "positive reappraisal" related positively to receipt of social support. The key coping strategy for hemophiliacs with AIDS and their family caregivers, "seeking support," was directed at specific support functions or sources; they most frequently sought informational support. In contrast, men with hemophilia and AIDS who coped by avoiding others, rather than by seeking support, did so because of fear of negative reaction and concern about confidentiality. For persons admitted for IHD, "seeking support" was also the most common coping strategy.

In contrast, most coping behaviours used by young children undergoing a painful procedure were directed at self-protection, and less often included support-seeking. Persons skilled at seeking support are more effective than others in obtaining it; however, coping is a developmental skill that may not be learned until adolescence or adulthood. Nevertheless, the coping behaviours of these young children were influenced by supportive interactions with nurses, and their level of preparation for the procedure was positively related to their ability to seek informational support, again suggesting links between coping and social support.

The support interventions for hemophiliacs with AIDS and their family caregivers, for MI survivors and their spouses, and for family caregivers of stroke survivors helped them cope with the demands of a chronic condition. Those living with HIV/AIDS reported increased problem-focused coping and actions, particularly seeking information and advocacy. Peer visitors explained about coping strategies to caregivers of stroke survivors; caregivers noted improved information-seeking and distraction from stress. The couples coping with MI reported enhanced problem-focused and relationship-focused coping.

We found that coping strategies can also be relationship-focused. In close support relationships, the coping of one partner influences the coping behaviours of the other (Gottlieb & Wagner, 1991). Evidence of "relationship coping" was revealed in the mothers' appraisal of interactions with the child's father. Mothers described their efforts to keep

the marriage together and cope with their spouse's lack of involvement in caring for the child with a chronic condition. They used "active engagement" (shared problem-solving and open discussion) or "protective buffering" (protecting the spouse from the demands of caregiving) (Coyne & Downey, 1991) to cope with such relationship stressors. Couples dealing with MI reported using more active engagement following the education-support intervention. Hemophiliacs with AIDS and their family caregivers used primarily coping strategies to keep their "personal relationships normal"; absent support and conflicted support in their relationships were predominant stressors. In contrast, participants with heart failure and stroke, who were on average 69 years of age and married for 40 years, reported experiencing stressors and support as a couple and satisfaction with their spousal relationship — possibly reflecting mastery of relationship coping in long-term, stable relationships.

Impact of Social Support on Health, Health Behaviour, and Use of Health Services

In Figure 1, the two-way arrow between social support and health depicts a bidirectional relationship. The arrow from support to health indicates that integration in a social network, and the ability to draw support resources from the network, can maintain health and facilitate recovery (Bloom, 1990). There is evidence that social support enhances health outcomes and reduces mortality, whereas stressful social relationships can prolong physical dysfunction (Kaplan & Toshima, 1990). Furthermore, negative interactions are more predictive of depression and poor emotional health than supportive interactions (Coyne & Downey, 1991; Rook, 1990). Socially integrated persons are less likely to have high rates of schizophrenia, depression, tuberculosis, hypertension, accidents, and pregnancy complications (Ford & Procidano, 1990; House et al., 1988).

In this research program, proximal health outcomes were classified as physical, psychological, and social. Consistent with the buffering model (Quittner, Glueckouf, & Jackson, 1990), our intervention trials hypothesize that support will have a moderating impact on health outcomes in the context of chronic stressors. The face-to-face-support intervention for couples coping with MI decreased negative affect of spouses. The pilot for another intervention suggested that telephone support for persons living with AIDS can enhance psychological health by decreasing social and emotional loneliness. Finally, the ongoing telephone-support groups for parents of young chronically ill children

are predicted to enhance parents' psychological health and their perceived caregiving competence.

Two assessment studies revealed that support was associated positively with the health of nurses. Increased total support and work-related support were found to be related to diminished burnout among community health nurses, and emotional support was negatively associated with emotional exhaustion (a component of burnout) among nurses working in AIDS care.

The arrow from health to social support indicates that health and illness affect availability and quality of social support. Illness is a major stressor, involving loss of relationships, status, independence, ability to work, and social mobility, as well as threat of death and loss of a loved one. The continued need for social support in chronic stressful situations such as illness can deplete support, drain the social network of resources that contribute to support, and result in alienation and estrangement (Stewart, 1993). Thus support can diminish over time. In one of the studies in the program, men with hemophilia and AIDS and their family caregivers reported isolation and avoidance by formerly supportive friends. In another, mothers of children with a chronic illness, particularly those facing extensive caregiving demands, reported lack of anticipated support from members of their network. One investigation found that persons re-admitted for IHD reported less support from neighbours than those admitted for the first time, perhaps because of their diminished ability to reciprocate.

The arrow from social support to health outcomes indicates the projected impact of support. Members of a social network may influence health behaviour directly by providing information and indirectly by encouraging compliance with regimens and maintenance of healthful behaviours; they can provide advice, act as a role model, or discourage inappropriate health behaviours (Bloom, 1990). Zimmerman and Connor (1989) found the greatest influences on health behaviour to be supportiveness, encouragement, and exemplary behaviour, on the part of family members, friends, and co-workers. Intervention studies have shown that support from family members and others can result in smoking cessation, weight loss, blood pressure control, and improved diet.

The face-to-face support for couples coping with MI resulted in increased perceived efficacy to make requisite lifestyle and health changes. Spouses and survivors reported increased confidence. However, negative outcomes, such as reinforcement of poor health behaviours or diminished self-care, can also result from network inter-

actions. For example, mothers expressed concern about the impact of interactions with peers on self-care and adherence to regimens among adolescents with diabetes or cystic fibrosis.

Finally, the arrow from health/functioning to use of health services indicates that members of the social network can influence use of health services by providing support, acting as screening and referral agents, and sharing help-seeking values associated with mobilization of support (Dunkel-Schetter & Bennett, 1990).

Seeking "formal" support from health professionals may not always be appropriate. The investigators conducting the study with family caregivers of stroke survivors anticipated that those who received peer support would be less likely to seek "inappropriate" professional intervention. Use of health services was measured through pre-test, post-test, and delayed post-test interviews. Significant decreases were noted, from pre-intervention to six-month interviews, in phone calls to physicians and in visits to physicians' offices and hospitals. Another study found that mothers discussed their need for support with caregiving demands pertaining to clinic appointments and to the use of health services. Thus support for family caregivers may influence the client's use of health services. This indirect influence might be taken into account when support interventions are being planned.

Summary and Conclusion

This program has yielded new insights and reinforced earlier research (see Table 2). The complex conceptual linkages among coping, stress, social support, and health require further study. Clinically relevant and feasible assessment strategies for nursing are needed; furthermore, the impact of nursing interventions that mobilize and foster social support require testing.

Table 2 *Themes Emerging from Assessment and Intervention Studies*

Themes Emerging from Assessment Studies

- Different types of providers for different types of support
- Support from both professionals and peers
- In chronic stressful situations, support can dissipate over time
- Delayed or altered reciprocity is acceptable in close relationships
- Chronic stressful situations can lead to problems with support from partners, friends, and professionals
- The coping strategy "seeking support" is positively related to social support; relationship coping strategies can help maintain network relationships
- Members of the social network can affect health behaviours both positively and negatively
- Support to family caregivers can affect recipients' use of health services
- Certain types of social support are associated with indicators of nursing burnout

Themes Emerging from Intervention Studies

- Different modes for different people
- Satisfaction with interventions: peers, professionals, participants
- Support processes: social comparison, social exchange, social learning
- Peer-professional partnership
- Support intervention outcomes (quantitative)
 - Loneliness ↓
 - Negative affect ↓
 - Social support need ↓
 - Social support satisfaction ↑
 - Use of health services ↓
- Perceived benefits (qualitative)
 - Talking with someone with similar experience
 - Knowing others in same situation
 - Affirmation and encouragement
 - Increased confidence, competence, empowerment
 - Enhanced communication
 - Satisfaction of emotional support needs
 - Satisfaction of information needs — knowledge ↑
 - Impact on coping → moved to action
 - Impact on interactions within natural network
 - Comfort in relationships with peers
 - Friendship/companionship

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All correspondence should be addressed to Dr. Miriam J. Stewart, Dalhousie University, 5981 University Avenue, Halifax, Nova Scotia B3H 3J5 Canada.

Erratum

In the article "Centres for Health Promotion Research in Canada," by Miriam Stewart (Volume 29, No. 1, Spring 1997), the valuable contributions of Judith Kulig, Regional Centre for Health Promotion and Community Studies; Michel O'Neill, Groupe de recherche et d'intervention en promotion de la santé de l'Université Laval; and Cynthia Smith, Alberta Centre for Well-Being, were inadvertently omitted from the Acknowledgements.

Annotated Bibliography: Studies Evaluating Decision-Support Interventions for Patients

**Annette M. O'Connor, Elizabeth R. Drake,
Valerie J. Fiset, Jacqueline Page, Diane Curtin,
and Hilary A. Llewellyn-Thomas**

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)

Annette M. O'Connor, R.N., Ph.D., is Professor and Ontario Ministry of Health Career Scientist, University of Ottawa School of Nursing. Elizabeth R. Drake, B.A., M.H.A., is Research Program Coordinator, Ottawa Civic Hospital Loeb Research Institute. Valerie J. Fiset, R.N., B.Sc.(N), Jacqueline Page, R.N., B.Sc.(N), and Diane Curtin, R.N., B.Sc.(N), are graduate students at the University of Ottawa. Hilary A. Llewellyn-Thomas R.N., B.Sc., M.Sc., Ph.D., is Professor, Faculty of Nursing, University of Toronto, and Senior Scientist, Clinical Epidemiology Unit, Sunnybrook Health Science Centre, Toronto.

- impact of decision support on decision (coded as unchanged, changed, mixed, other, including direction where applicable)

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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.

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Counselling, 15, 249–259. **Keywords:** patients with epilepsy; to take antiepileptic or not; variation in information disclosure (reasonable person versus 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;

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.

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Call for Papers

Gerontology

Summer 1998 (vol. 30, no. 2)

This issue will feature research that focuses on older people. Of interest are studies that increase our understanding of what people experience and perceive as needs as they age and research studies that contribute to our knowledge of how to care for or assist older people and their informal caregivers. Papers that describe new ways of conceptualizing nursing of older people and research that is needed within these frameworks are also welcome.

Guest Editor: Dr. Dorothy Pringle

Submission Deadline: January 15, 1998

Early Family Development

Fall 1998 (vol. 30, no. 3)

The focus of this issue is families during the early child-rearing years, with particular emphasis on the developing child. Topics include: the ecological environment of young children; developing and changing roles and relationships within the family (e.g., parent-child, sibling, grandparents), across situations and settings; cultural diversity in child-rearing practices; coping with transitional events (e.g., pregnancy, birth of a sibling, day care, school entry); changing family structures and demographics; early interventions with high-risk and at-risk families; and educational and health programs that promote family and child health. Qualitative and quantitative research reports as well as state-of-the-art reviews are invited.

Guest editor: Dr. Kathryn Barnard

Submission Deadline: April 15, 1998

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Articles à publier

Gérontologie

Été 1998 (vol. 30, no. 2)

Ce numéro se penche sur la question des familles dont les enfants sont en bas âge, avec un accent sur l'enfant en cours de développement. Les sujets incluent : l'environnement écologique des jeunes enfants; le développement et la transformation des rôles et des relations au sein de la famille (p. ex. parent-enfant, frère-soeur, grands-parents) dans le cadre de différentes situations et des contextes variés; la manifestation de diversités culturelles dans les pratiques d'éducation des enfants; l'habileté d'adaptation aux événements transitionnels (p. ex. la grossesse, la naissance d'un frère-une soeur, la garderie, l'entrée à l'école); les structures familiales en transformation et la démographie; l'intervention précoce auprès des familles vivant des situations à risque moyen et à risque élevé; et les programmes d'éducation et de santé qui promeuvent la santé de la famille et de l'enfant. Nous demandons des rapports de recherche d'ordre qualitatif et quantitatif, ainsi que des articles critiques de fine pointe.

Rédactrice invitée: Dorothy Pringle, Ph.D.

Date limite pour les soumissions: le 15 janvier 1998

Développement de la jeune famille

Automne 1998 (vol. 30, no. 3)

L'objectif du présent numéro est de participer à l'approfondissement de la connaissance en sciences infirmières sur les différents systèmes de soins prodigués aux usagés ainsi que leur mis en pratique au niveau de l'organisation, de la prestation et de l'évaluation des soins. On recherche surtout les sujets qui permettraient d'améliorer le développement et la mis en place de systèmes d'information ainsi que des études d'utilisation et d'implantation de tels systèmes. Ces sujets présentent un très grand intérêt.

Rédactrice invitée : Kathryn Barnard, Ph.D.

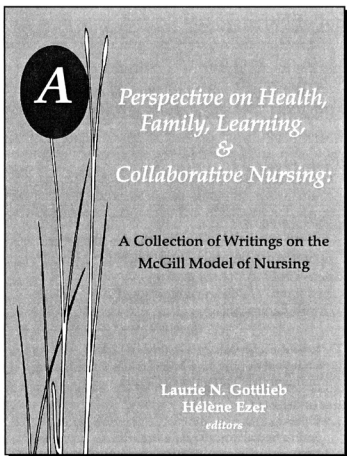
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University of British Columbia

SCHOOL OF NURSING

Faculty Positions Available

The University of British Columbia invites applications for three tenure-track faculty positions in the School of Nursing; two positions to be hired at the Instructor level, and one position available at Assistant Professor level.

For Instructor positions: Candidates should have extensive (3-5 years) clinical teaching experience with baccalaureate nursing students in a university environment, and have demonstrated ability for course leadership and supervision of clinical associate faculty involved in teaching. Teaching experience with masters students is desirable. A doctorate in nursing or a related field is desirable, although not required. Candidates should have an identified area of scholarship and/or advanced professional practice within perinatal, pediatric or psychiatric-mental health nursing, and evidence of professional contribution to their field.

For Assistant Professor position: A doctorate degree in Nursing or a related discipline (earned or near completion) is required; a masters degree in Nursing is also required. Applicants should have relevant recent teaching and clinical experience in mental health or adult health nursing (especially inpatient acute/critical care). Candidates will be expected to establish and pursue a program of research in their chosen specialty area, and should have evidence of professional and scientific contribution to their field.

The UBC School of Nursing has a long-standing tradition of excellence in undergraduate and graduate nursing education, and a strong commitment to advanced professional practice, scholarship and research. It offers programs leading to baccalaureate, masters and doctoral Nursing degrees and has affiliations with a wide range of hospitals and community agencies. The School currently has 450 undergraduate students, 150 masters students and 16 doctoral students enrolled, with a complement of 54 faculty. A new multiple-entry option BSN program has been launched on a pilot basis with full implementation expected in 1999.

The successful applicant will have teaching responsibilities in both the undergraduate and graduate programs. These positions are available, effective 1 January 1998. The appointments are subject to final budgetary approval. In accordance with Canadian Immigration requirements, priority for the Instructor-level positions will be given to Canadian citizens and permanent residents of Canada, while the Assistant Professor-level position is available to qualified non-Canadians. The University of British Columbia hires on the basis of merit and is committed to employment equity. All qualified persons are encouraged to apply. Applications, accompanied by a curriculum vitae and the names and addresses of three references, should be sent to:

Dr. Katharyn A. May
School of Nursing, University of British Columbia
T201-2211 Westbrook Mall, Vancouver, BC V6T 2B5
Tel: 604-822-7748 Fax: 604-822-7423

St. Francis Xavier University

FACULTY POSITIONS

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Applications are invited for one probationary tenure-track position and one nine-month limited term sabbatical replacement beginning September, 1998. Salary and rank will be commensurate with qualifications and experience.

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Initial teaching responsibilities will be with the on-campus, B.Sc.N. program. Opportunity is also available for teaching in the distance-education programs.

Minimum academic preparation and qualifications include a Master's degree in nursing, a doctorate in nursing, teaching experience at the undergraduate level, a strong practice focus in community and adult nursing, evidence of research and scholarly productivity, and eligibility for registration with the Registered Nurses Association of Nova Scotia.

The applications deadline is February 15, 1998. Please submit a cover letter, a curriculum vitae, a copy of current registration, and the names of three referees, including most recent employer, to:

Dr. Angela Gillis, Chair
Department of Nursing
St. Francis Xavier University
Box 5000, Antigonish, Nova Scotia B2G 2W5
Fax (902) 867-2322

In accordance with Canadian immigration requirements, priority will be given to Canadian citizens and permanent residents of Canada. St. Francis Xavier University is committed to employment equity.

The University of Western Ontario

SOCIOLOGY/HEALTH SCIENCES

The Department of Sociology and the Faculty of Health Sciences invite applications for a tenure-track position at the rank of Assistant Professor. This position is a joint appointment between the two units. Candidates must have a Ph.D. and show evidence of strong research potential and excellence in teaching. Applicants with expertise in the sociology of health, the sociology of aging, community health, or the social determinants of health are particularly encouraged to apply. Both graduate and undergraduate teaching are involved, and the candidate is expected to be committed to interdisciplinary research in the areas of health and aging.

*Interested candidates should send their curriculum vitae
and the names of three references to:*

Chair, Joint Search Committee, Department of Sociology
Social Science Centre, University of Western Ontario
London, Ontario N6A 5C2 Canada.

The closing date is January 15, 1998.

In accordance with Canadian immigration requirements, this advertisement is directed to Canadian citizens and permanent residents of Canada. The University of Western Ontario is committed to employment equity, welcomes diversity in the workplace, and encourages applications from all qualified individuals, including women, members of visible minorities, aboriginal persons, and persons with disabilities. The position is subject to budget approval.

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The *Canadian Journal of Nursing Research* is a quarterly journal. Its primary mandate is to publish nursing research that develops basic knowledge for the discipline and examines the application of the knowledge in practice. It also accepts research related to education and history and welcomes methodological, theory, and review papers that advance nursing science. Letters or commentaries about published articles are encouraged.

Procedure: Three double-spaced typewritten copies of the manuscript on 8 1/2" x 11" paper are required. Articles may be written in French or English. Authors are requested not to put their name in the body of the text, which will be submitted for blind review. Only unpublished manuscripts are accepted. A written statement assigning copyright of the manuscript to the *Canadian Journal of Nursing Research* must accompany all submissions to the journal. Manuscripts are sent to: The Editor, *Canadian Journal of Nursing Research*, School of Nursing, McGill University, 3506 University Street, Montreal, QC H3A 2A7.

Manuscripts

All manuscripts must follow the fourth edition of the *Publication Manual of the American Psychological Association*. Research articles must follow the APA format for presentation of the literature review, research questions and hypotheses, method, and discussion. All articles must adhere to APA guidelines for references, tables, and figures. Do not use footnotes.

Title page: This should include author name(s), degrees, position, information on financial assistance, acknowledgements, requests for reprints, address, and present affiliation.

Abstract: Research articles must include a summary of 100–150 words containing information on the purpose, design, sample, findings, and implications. Theory and review papers must include a statement of the principal issue(s), the framework for analysis, and a summary of the argument.

Text: The text should not exceed 15 double-spaced typed pages. References, tables, and figures should follow the text.

References: The references are listed in alphabetical order, double-spaced, and placed immediately following the text. Author names and journal citations must be spelled out in full.

Tables and figures: Tables and figures should appear only when absolutely necessary. They must be self-explanatory and summarize relevant information without duplicating the content of the text. Each table must include a short title, omit abbreviations, and be typed on a separate page. Figures must be in camera-ready form.

Review process and publication information: The *Canadian Journal of Nursing Research* is a peer-reviewed journal. Manuscripts are submitted to two reviewers for blind review. The first author will be notified following the review process, which takes approximately 12 weeks to complete.

Electronic copy: Authors must provide satisfactory electronic files of the accepted final version of the manuscript.

Renseignements à l'intention des auteurs

La *Revue canadienne de recherche en sciences infirmières* paraît quatre fois par année. Son mandat est de publier la recherche en sciences infirmières qui a trait au développement des connaissances dans la discipline et l'analyse de la mise en pratique de ces connaissances. La revue accepte également des articles de recherche reliés à l'éducation, à l'histoire de même que des articles reliés à la méthodologie, la théorie et l'analyse critique qui permettent le développement des sciences infirmières. Des lettres et commentaires sur des articles publiés sont également encouragés.

Modalités : Les textes doivent être soumis en trois exemplaires, être dactylographiés à double interligne sur des feuilles 216mm x 279 mm et être adressés à la rédactrice en chef, à la *Revue canadienne de recherche en sciences infirmières*, Université McGill, École des sciences infirmières, 3506 rue Université, Montréal, QC, H3A 2A7. Il est entendu que les articles soumis n'ont pas été simultanément présentés à d'autres revues. Veuillez également inclure lors de la soumission, une déclaration de propriété et de cession de droits d'auteurs. Finalement, afin de garder l'anonymat lors du processus de révision, veuillez ne pas inclure les noms des auteurs dans le texte.

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La présentation du manuscrit doit respecter les normes du *Publication Manual of the American Psychological Association*, 4^{ème} édition, 1994. Particulièrement, les figures, tableaux, illustrations et références doivent suivre ces normes de présentation. Il est suggéré de ne pas utiliser de notes au bas de la page.

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Résumé : Un résumé en anglais et en français d'environ 100 à 150 mots chacun doit précéder le texte. Ce résumé devrait comprendre l'objectif, la méthode, les résultats et les retombées de la recherche. Les manuscrits qui concernent la théorie et les analyses critiques doivent inclure une identification des objectifs principaux, le cadre conceptuel utilisé pour l'analyse des données et un résumé de la discussion. La qualité du français est primordiale; le style doit être clair concis et doit éviter un langage sexiste ou discriminatoire.

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