
CANADIAN ONCOLOGY NURSING JOURNAL

REVUE CANADIENNE DE SOINS INFIRMIERS EN ONCOLOGIE

FALL/AUTOMNE 2001

VOLUME 11, NO. 4

ISSN: 1181-912X



The official publication of **CANADIAN ASSOCIATION OF NURSES IN ONCOLOGY**
La publication officielle de **L'ASSOCIATION CANADIENNE DES INFIRMIÈRES EN ONCOLOGIE**

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A publication of the Canadian Association of Nurses in Oncology

Une publication de l'Association canadienne des infirmières en oncologie

Canadian Oncology Nursing Journal/Revue canadienne de soins infirmiers en oncologie is a refereed journal.

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- Statement of Purpose** The Canadian Oncology Nursing Journal is the official publication of the Canadian Association of Nurses in Oncology, and is directed to the professional nurse caring for patients with cancer. The journal supports the philosophy of the national association. The philosophy is: *"The purpose of this journal is to communicate with the members of the Association. This journal currently acts as a vehicle for news related to clinical oncology practice, technology, education and research. This journal aims to publish timely papers, to promote the image of the nurse involved in cancer care, to stimulate nursing issues in oncology nursing, and to encourage nurses to publish in national media."* In addition, the journal serves as a newsletter conveying information related to The Canadian Association of Nurses in Oncology; it intends to keep Canadian oncology nurses current in the activities of their national association. Recognizing the value of nursing literature, the editorial board will collaborate with editorial boards of other journals and indexes to increase the quality and accessibility of nursing literature.
- Indexing** The Canadian Oncology Nursing Journal/Revue canadienne de soins infirmiers en oncologie is registered with the National Library of Canada, ISSN 1181-912X, and is indexed in the Cumulative Index to Nursing and Allied Health Literature, (CINAHL), the International Nursing Index and Medline.
- Membership** All nurses with active Canadian registration are eligible for membership in CANO. Contact the CANO national office. Refer to the Communiqué section for name and contact information of provincial representatives.
- Subscriptions** The journal is published quarterly in February, May, August and November. All CANO members receive the journal. For non-members, yearly subscription rates are \$90.95 (GST included)/\$97.75 (HST included) for individuals, and \$101.65 (GST included)/\$109.25 (HST included) for institutions. International subscriptions are \$115.00. Payment must accompany all orders and is not refundable. Make cheques payable to CANO-CONJ and send to the CANO national office, **Canadian Association of Nurses in Oncology, 232 - 329 March Road, Box 11, Kanata, ON, K2K 2E1 Telephone: (613) 270-0711, Fax: (613) 599-7027, E-mail: canoacio@igs.net**
- Author Information** Guidelines for authors are usually included in each issue. All submissions are welcome. At least one author should be a registered nurse, however, the editor has final discretion on suitability for inclusion. Author(s) are responsible for acknowledging all sources of funding and/or information.
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REVUE CANADIENNE DE SOINS INFIRMIERS EN ONCOLOGIE

Guest editorial

Outgoing president's message 2001

Honoured guests, CANO members, and conference participants, as president I am excited to welcome you this morning to this first-ever CANO/ACIO conference in Quebec, a lucky 13th conference of the Canadian Association of Nurses in Oncology.

The conference planning committee, Andréanne Saucier, Linda Hershon, and Marie de Serres have worked very hard over the past year to organize this conference, and, judging by the number of registrants and the excellence of the papers submitted, we have much to look forward to over these next few days.

This morning, I invite you to go back with me on a journey that started for some of you quite some time ago and for others, not so long ago. Close your eyes for just a minute and try to remember your first day of nursing school. What were your hopes and dreams for yourself? Did you wonder then what kind of nurse you would be? Did you ever think you would specialize in oncology nursing?

Can you remember your feelings the first time you cared for a patient who was in severe pain or vomiting and it seemed as if nothing you did helped? How you realized you had so much more to learn if you were really going to be able to comfort your patients? We can all likely remember our first clumsy attempts at starting an IV, doing a dressing, or fumbling with that very frightening question that would quietly slip from our patients' lips, "Nurse, do you think I am going to get better?"

I'm sure no one where I went to school would have predicted a career in oncology for me. As a student nurse in my very early months of school, and these were the days when bone marrow aspirates were done in the sternum, I fainted dead away and fell right on top of the sterile field and the astonished patient! It took some courage to turn around and come back the next day!

But we all moved on from those first clumsy attempts, gaining expertise, learning more about human nature, and developing insight about ourselves in the process. As nurses, we got our rewards from a catheter that went into a vein as smoothly as a knife through butter, a pain score that was going down, not up, the excitement of sharing the news with a patient when she hears the scan is negative, and the hand that reaches for ours when the news is not so good.

When we are first learning the art and

science of nursing, we focus on anatomy and physiology and understanding how diseases and treatments work. But once you got comfortable doing these things, you likely started to reach out for other challenges. You went to conferences and workshops to hear the stories of other nurses and learn from them. If you were lucky, as I was, you found yourself working in an environment where you were encouraged to try new ways of doing things, to participate in research studies, and to join committees and organizations like CANO.

If you were really fortunate, you had a mentor, someone who challenged you to move beyond your present level of comfort. So as you think about your journey in oncology nursing, are you where you want to be? Do you have more to learn, more to give? Is there room for growth? Do you have the courage to step forward and be a mentor or a student again? I assure you that your profession and your patients need your skill, knowledge, and commitment now more than ever. Organizations like CANO offer you opportunities to be both a student and a mentor.

When we were students, I think we believed we would know it all once we received that important "RN" designation, but we quickly learned it was only the beginning of a lifetime of learning. Almost 30 years after my own graduation, I had the very wonderful experience of attending the graduation from university of my own son. Not so remarkable a feat you might think, but the amazing thing to me was that on that same day, one of my dear friends, who graduated with me all those years ago from nursing school, was receiving her bachelors degree in nursing from the University of Victoria, and another close friend, whom I had met when we worked together at the Tom Baker Cancer Centre, had just successfully defended her Masters in nursing thesis. This is a sure sign to me of the ongoing nature of the learning process and the commitment that so many nurses make to the profession and their patients.

But where do you find yourself now? Many of us are working in an almost toxic or hostile health care environment. We find ourselves facing severe shortages of nurses and other health professionals and caring for an increasingly demanding and educated public. In too many oncology settings, the move to a "business unit" philosophy and the resulting downsizing have left few nursing positions that have any real power. It is my opinion that we have assumed that health care could be run in the same manner as car factories and we have been "reprocessed" and "re-

engineered" until it has felt as if the heart of good patient care has been relegated to the plant waste bin.

Cancer care has long been traditionally based on a very medical model of care and one where nurses often find themselves not as decision-makers, but as second-class citizens. Too often we are not invited to the table to have our opinion heard. In the report of the Human Resources Planning Working Group to the Canadian Strategy for Cancer Control, nurses were described as a "supportive and contributory discipline." Yet, I would assert that oncology nurses are at the very core of oncology care in this country.

It is in these, our difficult moments, when the focus in the media is on nurses as numerous provinces have endured nursing job action and withdrawals of service, that we have our greatest opportunity to be heard and to make changes. The difficulties are the very opportunities that we must now seize if we want to ensure that the health care system will allow us to be the kind of nurses we dreamed about becoming on our first day of nursing school.

Sustaining that system will require professional organizations like ours that will advocate for what is best for patient care. I urge all of us to think of our organizations as more than getting a journal, or accessing a website, or signing up for a conference or a course. If that were all oncology nursing in Canada needed, then it would be better if we folded our tent right now and joined our American colleagues in ONS. But as oncology nurses working in Canada, you need far more than these things. You need to have your voice heard, and a single voice crying out in your particular wilderness will not work. We need to be united in our numbers to become a strong lobby force. We heard at our conference last year about finding our voice and we must do this as a national group.

Over the summer holidays, I happened to hear Shirley Douglas interviewed on CBC Radio. You likely remember Shirley as the Canadian actress who most recently played the grandmother on "Wind at My Back," but she is also a founder of "Friends of Medicare" and the daughter of Tommy Douglas, the Saskatchewan premier who founded Medicare in Canada. She was commenting on the need of nurses, in particular, to become engaged in the advocacy that is needed to reform health care. She stated, and I quote from memory, "If you are a nurse and you used to work on a hospital unit where there were 30 of you and now there are seven - how did you let that happen? If you are told to send a patient home who is too sick

to go, why don't you say no?" She commented that she hears nurses say, "I'm just a nurse, I'm not political." She reminds us that to live in a society is to be political and she urges nurses to not stand by and accept less for our patients.

We must define what our own nursing practice is and what educational preparation and competencies are needed to do our work. If you don't define it for yourself, another professional or administrator will be happy to do it for you! We must, and I feel passionately about this, we **must** do a better job of mentoring each other so that the future nurses who will be working at the bedside, in the chemotherapy and radiotherapy clinics, in the emergency departments, and in the board rooms will have the confidence and the skills to speak out about what is good for patient care.

So what is CANO/ACIO doing to address these serious challenges? We have been extremely fortunate to maintain our membership base of approximately 900 nurses. The past year has been an extremely busy one for the executive and board of CANO/ACIO, with many special projects and activities which you will see featured in sessions throughout the conference. The generous educational grant by Astra Zeneca allowed us to begin work two years ago on an important and ambitious five-year CANO Oncology National Education Project (CONEP) which is developing a detailed strategic plan to support basic specialty and advanced role development. In this first phase of the project, the initiative has realized position statements on the specialty of oncology nursing and advanced practice, role statements on levels of oncology nursing, and competency statements of basic specialty and advanced oncology nurses. Later phases will focus on validation of the new standards by patients and other professionals, the strategies needed to implement the oncology nursing roles, and the urgently required program of research to study the impact of oncology nursing on patient outcomes. This initiative has produced a document entitled Standards of Care, Roles in Oncology Nursing and Role Competencies, which will be distributed to oncology and educational settings in Canada. In addition, as part of the ongoing commitment to oncology nursing, Astra Zeneca has inaugurated support for a number of travel and educational grants and scholarships over the next three years.

Intensive work continued in the final year of the CANO/ACIO National Pain Initiative, a three-year project funded by Janssen Ortho Inc. that will result in a comprehensive pain program for use by oncology nurses in our country.

CANO/ACIO members represented oncology nursing on various committees of the Canadian Breast Cancer Initiative. This is an initiative funded by the federal government to work in collaboration with stakeholders, partners, and those affected by breast cancer to reduce the incidence of breast cancer, reduce mortality as a result of breast cancer, and improve the quality of life of those affected by breast cancer and their support networks.

In partnership with Janssen Ortho Inc., CANO/ACIO is commencing further work on the development of activities in the area of cancer-related fatigue. Plans are underway for an interactive website where nurses will be able to access information and post questions.

We continue to be involved in many external boards and committees too numerous to mention. I want to express my profound thanks to the many CANO/ACIO members who have committed to represent you on these committees, boards, and initiatives. Please make sure that you look through the annual report and make the effort to meet and thank these CANO/ACIO leaders.

At the awards ceremony, you will see that CANO/ACIO continues to recognize members through the awarding of the Schering and Helene Hudson Memorial lectureships, the CANO/Pharmacia awards of excellence in administration, research, education, and clinical practice, and awards for innovation in patient education. I am most pleased that at this conference we will be announcing a major new award sponsored by Eli Lilly, called the CANO/ACIO Eli Lilly Leadership in Oncology Nursing Mentorship Award, which will foster the development of leadership skills in the areas of clinical practice, education, research, and administration.

CANO/ACIO has had significant involvement in the Canadian Strategy for Cancer Control, an initiative spearheaded by Health Canada, the Canadian Cancer Society, and the Canadian Association of Provincial Cancer Agencies, as well as numerous professional and advocacy groups. CANO/ACIO has recently appointed members to two national advisory committees which have evolved from the strategy meetings held in Ottawa; one on human resources planning and another on systemic therapy.

I would like to quote from the submission published in this year's annual report by Kim Chapman and Esther Green regarding CANO's/ACIO's future role in the strategy, "Being part of the strategy, especially the integration group, provided CANO/ACIO with some incredible opportunities. CANO's/ACIO's presence

allowed us to increase awareness and educate members of the cancer community about nursing's significant contribution to cancer care across varied settings and in all phases of the cancer experience. Nurses have been, and will continue to be, leaders in the delivery of innovative cancer care. Through varied discussions, we were able to share our vision for oncology nursing, ensuring strategy recommendations help us realize our vision. Most importantly, we were there to speak for nursing. We were able to guide and shape not only cancer control, but also what and how cancer nursing will look in a coordinated, comprehensive cancer control system. We know that future delivery of cancer care will create new opportunities for nurses in areas never before thought possible."

Now I want to turn towards the future for CANO as an organization. In an article published in **Nursing Administration Quarterly** about transformational leadership (Goertz Koerner & Schmidt Bunkers, 1992), the authors stated, "Choices come about when the things that have worked in the past no longer work. New answers are then needed." It is this belief that has driven your executive and board, along with many CANO members, to undertake a major project in strategic planning that resulted in a revised "Mission, Vision, and Values" statement and the development of strategic objectives over the next few years. The strategic directions are in six areas: membership recruitment, fiscal stability, leadership profile, patient advocacy, organizational infrastructure, and standards. The board recognized the urgency of moving forward this year on the issue of organizational infrastructure. For those of you who are CANO/ACIO members, you will have received a letter from me on behalf of the board outlining the proposed changes. I urge you to attend the annual meeting on Tuesday morning to hear about the exciting new directions CANO/ACIO is planning. I am convinced after four years of board involvement that we have no choice but to embrace change with courage and energy if we are to represent oncology nurses and improve cancer care in this country.

This conference is about telling stories, and before I invite your in-coming president, Esther Green, to address you, I would like to close my speech with a personal story of my own. A few years ago, I had the good fortune to attend a weeklong course in Victoria at Royal Roads University entitled Creative Leadership For Health Care Administrators. At the beginning of the week, as part of an interactive session, we

were asked to walk around a large conference room and stop and greet another participant whom we did not know. The exercise was then to spend the next 15 minutes telling this total stranger what we believed were the three most important things we wanted to see happen or accomplish before we died. I can tell you that when the instructions were read out there was somewhat of a stunned silence. I heard more than a few nervous laughs turn into hushed voices and later to tears, as we thought seriously about our deaths and the meaning of our lives. I knew instantly what these three things were, despite the fact that I had not previously formulated an answer.

For those of you who know me, you will not be surprised at my first hope: to be a grandmother! This I have to report has not happened and seems a remote possibility for some time. I did, however, have the wonderful surprise of having my kid sister have her first baby this year, a daughter who was born on my 50th birthday! Thus, I am getting to be an auntie-cum-grandmother. My second hope is to nurture a sense of inner peace, not an easy task and not one I expect I will ever be "finished with," but I am definitely making progress in my spiritual journey.

My third hope was that I knew it was important to me to give something back to the community and to the profession of nursing which had given so much to me. Nursing has shaped who I have become and how my life has evolved. Following that course, I then committed to seek opportunities within CANO/ACIO that would allow me to give back to nursing. Thus, in serving on the CANO/ACIO board for the last four years and as president for the last two years, I have hopefully been given a chance to realize a portion of my goal. Not surprisingly, it is surely me who has grown and been nurtured by you the members and the board and executive during this last four years. The many, kind words, the hundreds of e-mails, the "honks" of encouragement, have sustained me through a challenging and sometimes difficult last two years. The experience of serving on the CANO board has increased my commitment to excellence in nursing and offered me the opportunity to meet so many dedicated and caring nurses from across this nation. I understand to a much greater extent the difficulties we face as a nation in remaining united, while respecting our real and unique differences. In closing, I applaud you my colleagues in Quebec, not just for this wonderful event you have planned for us this week, but for your ongoing and steadfast support of CANO/ACIO.

This lead goose is turning over the flock to my colleague Esther who has been a mentor to me and who I know will provide leadership and the courage to move us in new directions. Thank you all sincerely for the opportunity you have given me to represent you. During these next few days, share your stories with nurses who are your friends, mentors, and colleagues. Spend time thinking about what three things you might yet want to accomplish in the precious life which you have been given. Merci.

Carolyn Tayler,
CANO past-president

Reference

Goertz Koerner, J., & Schmidt Bunkers, S. (1992). Transformational leadership: The power of symbol. *Nursing Administration Quarterly*, 17(1), 1-9.

Éditorial d'une invitée spéciale

Message de la présidente sortante en 2001

Chers invités de marque, membres de l'ACIO et participants à la conférence: c'est pleine d'enthousiasme que je vous souhaite la bienvenue ce matin à la conférence annuelle de l'ACIO, qui se déroule au Québec pour la toute première fois; 13^e du nom, cette conférence ne pourra que porter bonheur à l'Association canadienne des infirmières en oncologie.

Le comité organisateur de la conférence, Andréanne Saucier, Linda Hershon et Marie de Serres ont travaillé très fort, au cours des douze derniers mois, à la préparation de cette conférence et si j'en juge par le nombre d'inscriptions et la qualité des articles soumis, les journées qui viennent seront des plus stimulantes.

Ce matin, je vous invite à faire un retour en arrière vers une époque qui pour certaines d'entre vous remonte à loin tandis que pour d'autres, elle concerne des temps plus récents. Fermez les yeux rien qu'une minute et essayez de vous souvenir de votre première journée à l'école d'infirmières ou de sciences infirmières. Quels espoirs et quels rêves entreteniez-vous à propos de votre propre avenir? Vous demandiez-vous quel type d'infirmière vous feriez? Pensiez-vous qu'un jour vous embrasseriez la

spécialité des soins infirmiers en oncologie?

Vous souvenez-vous de ce que vous avez ressenti la première fois que vous vous êtes occupée d'un patient qui souffrait de douleurs intenses ou qui vomissait et qu'aucune de vos interventions ne semblait l'aider? Vous souvenez-vous de la manière dont vous avez réalisé tout ce qu'il vous faudrait encore apprendre si vous vouliez vraiment reconforter vos patients? Il est fort probable que nous puissions toutes nous rappeler nos premières tentatives maladroites relatives à la mise en place d'une intraveineuse, à l'installation d'un pansement ou à l'ânonnement d'une réponse à la question terrifiante qui sortait tranquillement de la bouche de nos patients: "Infirmière, pensez-vous que mon état va s'améliorer?"

Je suis certaine que personne parmi mes condisciples et mes enseignantes ne m'aurait prédit une carrière en oncologie. Durant mes premiers mois d'élève-infirmière, et c'était à l'époque où les ponctions de la moelle osseuse se faisaient dans le sternum, je me suis complètement évanouie et je suis tombée en plein sur le champ aseptique au grand étonnement du patient! Cela m'a pris une forte dose de courage pour me remettre de mes émotions et retourner au travail le lendemain!

Mais nous avons toutes dépassé ces premières tentatives maladroites et la démarche nous a permis d'y gagner en expertise et de développer nos connaissances sur la nature humaine et sur nous-mêmes. Nos récompenses professionnelles prennent la forme d'un cathéter qui pénètre dans la veine aussi facilement qu'un couteau dans le beurre, d'une cotation des douleurs qui baisse plutôt que de monter, de l'excitation du partage de l'information avec une patiente lorsqu'on sait que la scintillographie est négative, et de la main qui se tend vers les nôtres lorsque les nouvelles ne sont pas aussi bonnes.

Lorsqu'on apprend l'art et la science des soins infirmiers, l'accent est mis sur l'anatomie et la physiologie et on cherche à comprendre le fonctionnement des maladies et des traitements. Mais une fois que l'on s'est familiarisée avec ces domaines, il est probable que l'on se fixe de nouveaux défis. C'est alors qu'on décide de participer à des conférences et à des ateliers afin d'entendre les récits d'autres infirmières et d'apprendre auprès d'elles. Si comme moi vous aviez de la chance, vous travailliez dans un environnement où l'on vous encourageait à essayer de nouvelles méthodes, à participer à des études de recherche, à

siéger à des comités et à adhérer à des organismes tels que l'ACIO.

Si vous étiez particulièrement chanceuse, vous aviez un mentor, quelqu'un qui vous poussait à sortir de votre zone de confort. Et pendant que vous êtes en train de penser à votre cheminement en soins infirmiers en oncologie, je vous incite à vous demander si vous êtes rendue là où vous souhaitez être? Avez-vous quelque chose d'autre à apprendre, quelque chose d'autre à donner? Avez-vous de quoi vous épanouir? Avez-vous le courage de marquer un pas en avant et de vous faire mentor ou de retourner aux études? Je peux vous assurer que votre profession et vos patients ont besoin, aujourd'hui plus que jamais, de vos compétences, de vos connaissances et de votre dévouement. Des organismes tels que l'ACIO vous offrent la possibilité de vous faire mentor et de retourner aux études.

Quand j'étais encore étudiante, j'ai bien l'impression que nous croyions que nous aurions acquis toutes les connaissances requises quand on nous décernerait la désignation d'infirmière autorisée, mais nous nous sommes vite aperçues qu'il ne s'agissait en fait que du début de l'apprentissage de toute une vie. Presque 30 ans après la fin de mes études, j'ai eu le grand honneur d'assister à la collation des grades universitaires dont mon propre fils faisait partie. Vous allez peut-être me dire qu'il ne s'agit pas d'un exploit si remarquable, mais ce qui m'étonnait le plus, c'est que, ce jour-là, l'une de mes meilleures amies, qui était sortie diplômée de l'école d'infirmières en même temps que moi il y a si longtemps, recevait son baccalauréat en soins infirmiers de l'Université de Victoria et qu'une autre amie intime que j'avais rencontrée lorsque nous travaillions ensemble au Tom Baker Cancer Centre, venait tout juste de défendre sa thèse de maîtrise en soins infirmiers. Ce signe ne trompe pas et il souligne la nature continue du processus d'apprentissage et de l'engagement qui rattache les infirmières à leur profession et à leurs patients.

Mais, où en êtes-vous actuellement? Nous sommes nombreuses à travailler dans un environnement de santé quasi toxique ou hostile. Nous devons faire face à de graves pénuries d'infirmières et d'autres professionnels de la santé et prodiguer des soins à un public toujours mieux informé et toujours plus exigeant. Dans un trop grand nombre de services d'oncologie, l'adoption d'une philosophie "d'unité fonctionnelle" et la réduction des effectifs qui a suivi n'ont épargné que peu de postes infirmiers ayant un pouvoir réel. D'après moi, nous

avons supposé qu'il était possible de gérer les soins de santé comme on gère des usines d'automobiles et nous avons subi des "restructurations" et des "remaniements" jusqu'à ce qu'il ne reste plus rien, qu'il semble que l'âme des soins au patient de qualité ait été jetée dans la poubelle de l'usine.

Depuis longtemps, les soins en cancérologie se fondent sur un modèle privilégiant à outrance l'aspect médical en vertu duquel les infirmières se voient obligées d'abandonner leurs statut de décideurs pour se cantonner à des rôles de seconde zone. C'est trop souvent que nous ne sommes pas invitées à donner notre avis lors de consultations. Le rapport adressé à la Stratégie canadienne de lutte contre le cancer par le Groupe de travail sur la planification des ressources humaines décrivait les infirmières comme formant une discipline auxiliaire. Selon moi, les infirmières en oncologie sont au cœur des soins en oncologie de notre pays.

Et c'est dans ces moments difficiles – alors que les infirmières font la une dans de nombreuses provinces en exerçant divers moyens de pression au travail et en interrompant leurs services, que nous avons l'occasion de nous faire entendre et de précipiter le changement. Ces difficultés représentent les opportunités qu'il nous faut saisir dès aujourd'hui si nous voulons que le système de soins de santé nous permette d'être le type d'infirmières que nous rêvions de devenir lors de notre première journée à l'école d'infirmières.

Le fonctionnement durable de ce système exigera des organismes professionnels comme le nôtre qu'ils fassent connaître leurs recommandations en matière de soins aux patients. Je vous encourage toutes à ne pas limiter votre conception des rôles de vos organismes à la réception d'une revue professionnelle, à l'accès à un site Web ou à l'inscription à une conférence ou à un cours. Si c'est à cela que se limitaient les besoins des soins infirmiers en oncologie du Canada, nous ferions mieux de fermer nos portes dès maintenant et de rejoindre au sein de l'ONS nos collègues des États-Unis. Mais les besoins des infirmières en oncologie vont bien au-delà de ces services; elles ont besoin de faire entendre leur voix collective car les voix individuelles qui s'élèvent à droite et à gauche ne suffisent pas. L'union fait la force; unies, nous constituerons un puissant groupe de pression. La conférence de l'an dernier nous conviait à trouver notre voix collective et c'est ce que nous devons faire en tant que groupe d'envergure nationale.

Durant les vacances de cet été, j'ai eu l'occasion d'écouter une interview de Shirley Douglas à l'antenne anglaise de Radio-Canada. Vous vous souviendrez probablement de cette actrice canadienne qui a récemment joué le rôle de la grand-mère dans la série télévisée "Wind at My Back"; elle fait également partie des fondateurs de l'organisme "Friends of Medicare" et est la fille de Tommy Douglas, l'ancien premier ministre de la Saskatchewan qui a créé le régime d'assurance-maladie du Canada. Elle expliquait que, dans le cas des infirmières, on était en droit d'attendre qu'elles s'engagent dans l'action revendicatrice requise pour stimuler la réforme des soins de santé. Elle a dit à peu près ceci puisque je la cite de mémoire: "Si vous êtes infirmière et que vous travailliez dans un service hospitalier où vous étiez 30 et que vous n'êtes plus que 7 – pourquoi ne vous y êtes-vous pas opposée? Lorsqu'on vous dit de donner son congé à un patient qui est encore trop souffrant, pourquoi ne dites-vous pas non?" Mme Douglas a fait remarquer que des infirmières s'expriment ainsi: "Je ne suis qu'une infirmière, je ne fais pas de politique." Elle nous rappelle que le fait de vivre en société est un acte politique et elle incite les infirmières à ne pas rester là sans rien faire et à ne pas accepter la détérioration des services aux patients.

Il nous faut définir notre propre pratique des soins infirmiers ainsi que les études et les compétences correspondant aux fonctions que nous remplissons. Si on ne le fait pas nous-mêmes, il y a d'autres professionnels ou des administrateurs qui se feront un plaisir de le faire à notre place! Il nous faut, et j'insiste bien sur ce point, il nous **faut** faire de plus gros efforts en matière de mentorat mutuel de manière à ce que les infirmières de demain qui travailleront au chevet des patients, dans les cliniques de chimiothérapie et de radiothérapie, dans les services d'urgence et au niveau de la haute direction posséderont la confiance et les compétences nécessaires pour parler de ce qui favorise les soins aux patients.

Qu'est-ce que l'ACIO projette de faire pour relever ces défis de taille? D'abord, nous avons la chance d'avoir pu maintenir le nombre de membres autour de 900 infirmières. L'année passée a été des plus chargées pour le Comité exécutif et le Conseil national de l'ACIO dans le cadre d'un grand nombre d'activités et de projets spéciaux qui seront au programme de plusieurs sessions de la conférence. La généreuse subvention de formation offerte par Astra Zeneca nous a

permis de lancer, il y a deux ans, les travaux d'un ambitieux et important projet quinquennal, le fameux CONEP [Projet de formation infirmière en oncologie de l'ACIO] dans le cadre duquel on élabore un plan stratégique détaillé en vue de développer les rôles liés à la spécialisation de base et à la pratique avancée. Durant sa première phase, le projet a produit des énoncés de position sur la spécialité des soins infirmiers en oncologie et sur la pratique avancée, sur les rôles relatifs aux divers niveaux de soins infirmiers en oncologie et sur les compétences des infirmières en oncologie, de l'infirmière spécialisée et de l'infirmière de niveau avancé. Les phases ultérieures porteront sur la validation des nouvelles normes par des patients et d'autres professionnels de la santé, sur les stratégies à utiliser pour mettre en œuvre les rôles en soins infirmiers en oncologie et sur la mise en route urgente du programme de recherche qui examinerait l'incidence des soins infirmiers en oncologie sur les résultats pour les patients. Cette initiative a produit un document intitulé *Normes pour les soins, Rôles en soins infirmiers en oncologie et Compétences relatives aux rôles*, qui sera diffusé dans les milieux de formation et de soins en oncologie du Canada. En outre, dans le cadre de son engagement continu en faveur des soins infirmiers en oncologie, Astra Zeneca a lancé un programme de soutien concernant plusieurs subventions et bourses de voyage et d'études qui s'échelonnent sur les trois prochaines années.

Les intenses travaux menés par l'Initiative nationale de l'ACIO sur la douleur se sont poursuivis durant la dernière année du projet triennal financé par Janssen Ortho Inc. qui se traduira par la mise au point d'un programme global sur la douleur lequel sera mis à la disposition des infirmières en oncologie du Canada.

Des membres de l'ACIO ont représenté les soins infirmiers en oncologie au sein de divers comités de l'Initiative canadienne pour la recherche sur le cancer du sein. Cette dernière est financée par le gouvernement fédéral et elle a pour mandat de travailler auprès des intervenants, des partenaires et des personnes touchées par le cancer du sein en vue de réduire l'incidence de ce cancer, d'en faire baisser la mortalité et d'améliorer la qualité de vie des personnes touchées par cette maladie et leurs réseaux de soutien.

C'est aussi en partenariat avec Janssen Ortho Inc. que l'ACIO lance de nouveaux travaux ayant trait à la conception

d'activités dans le domaine de la fatigue associée au cancer. On projette d'activer un site Web interactif où les infirmières pourront accéder à l'information disponible et poser des questions.

Nous continuons d'œuvrer au sein de plusieurs conseils d'administration et comités d'organismes extérieurs, en fait trop nombreux pour qu'on les mentionne tous. Je tiens à exprimer de sincères remerciements aux nombreux membres de l'ACIO qui nous ont représentés au sein de ces comités, conseils d'administration et initiatives. Je vous prierais de consulter le rapport annuel et de faire un effort pour rencontrer les chefs de file de l'ACIO et les remercier en personne.

À la cérémonie de remise des prix, vous verrez que l'ACIO continue de reconnaître le mérite de ses membres par le biais du Prix de conférence ACIO/Amgen à la mémoire de Helene Hudson et du Prix de conférence Schering, des prix d'excellence Pharmacia/l'ACIO en administration, en recherche, en formation et en pratique clinique ainsi que des prix d'innovation dans l'enseignement aux patients. De plus, je suis extrêmement heureuse de savoir que nous annoncerons dans le cadre de la présente conférence, un nouveau prix important parrainé par Eli Lilly et qui portera le nom suivant: *Prix de mentorat ACIO/Eli Lilly en leadership en soins infirmiers en oncologie*, qui favorisera le développement des aptitudes au leadership dans les domaines de la pratique clinique, de la formation, de la recherche et de l'administration.

L'ACIO a joué un rôle déterminant au sein de la Stratégie canadienne de lutte contre le cancer, initiative dirigée par Santé Canada, la Société canadienne du cancer et l'Association canadienne des organismes provinciaux de lutte contre le cancer ainsi que dans de nombreux regroupements professionnels et groupes de défense des intérêts. L'ACIO a récemment nommé ceux de ses membres qui siégeront à deux comités consultatifs nationaux qui sont nés des réunions de conception stratégique tenues à Ottawa; l'un sur la planification des ressources humaines et l'autre sur la thérapie systémique.

J'aimerais citer un extrait du rapport annuel de cette année que nous devons à M^{mes} Kim Chapman et Esther Green qui examinent le rôle futur de l'ACIO dans la Stratégie: "Le fait de faire partie de la Stratégie, particulièrement du Groupe d'intégration, a présenté d'incroyables opportunités à l'ACIO. Notre présence nous a permis de renseigner et de sensibiliser les membres de la

communauté du cancer sur l'importance de la contribution des soins infirmiers aux soins aux personnes atteintes de cancer et ce, dans les divers milieux de soins et dans toutes les phases de l'expérience du cancer. Les infirmières ont été et continueront d'être des chefs de file pour ce qui est de la prestation de soins novateurs en cancérologie. Divers débats nous ont permis de partager notre vision des soins infirmiers en oncologie et nous avons veillé à ce que les recommandations émanant de la Stratégie nous aident à concrétiser cette vision. Mais, plus important encore, nous avons pu parler des soins infirmiers. Nous avons pu orienter et façonner la lutte contre le cancer, mais aussi l'apparence que les soins infirmiers en oncologie revêtiront dans un système de lutte contre le cancer coordonné et global. Nous savons très bien que la prestation future des soins en cancérologie créera pour les infirmières de nouvelles possibilités dans des domaines auxquels il était impossible de penser jusqu'à présent."

Je voudrais maintenant me tourner vers l'avenir de l'ACIO en tant qu'organisme. Dans un article publié dans la revue *Nursing Administration Quarterly* à propos du leadership transformationnel (Goertz Koerner et Schmidt Bunkers, 1992), les auteurs écrivaient ceci: "Les choix se présentent lorsque ce qui fonctionnait par le passé cesse de donner de bons résultats. Il faut alors trouver de nouvelles réponses." C'est dans cette perspective que le Comité exécutif et le Conseil national, ainsi que de nombreux membres individuels de l'ACIO, ont entrepris un grand projet de planification stratégique qui a donné naissance à une révision des énoncés "Mission, Vision, et Valeurs" et à l'élaboration d'objectifs stratégiques au cours des prochaines années. Les orientations stratégiques concernent les six domaines ci-dessous: recrutement de membres, stabilité financière, profil du leadership, défense des intérêts des patients, infrastructure organisationnelle et normes. Le Conseil national a décidé qu'il était urgent de s'occuper, dès cette année, de l'infrastructure organisationnelle. Ceux et celles d'entre vous qui sont membres de l'ACIO ont reçu une lettre que j'ai signée au nom du Conseil national et dans laquelle nous dressons les grandes lignes des changements proposés. Je vous incite à assister, mardi matin, à l'Assemblée annuelle, pour vous renseigner sur les nouvelles orientations stimulantes que l'ACIO envisage. Après les quatre ans que j'ai passés au sein du Conseil national, je suis convaincue que nous

n'avons d'autre choix que celui d'embrasser le changement avec une bonne dose de courage et d'énergie si nous voulons représenter adéquatement les infirmières en oncologie et améliorer les soins aux personnes atteintes de cancer dans notre pays.

La conférence de cette année a pour thème "se raconter pour se découvrir" et avant d'inviter la nouvelle présidente, Esther Green, à prononcer son allocution, je voudrais terminer ma présentation sur une expérience personnelle. Il y a quelques années de ça, j'ai eu la chance de participer à un cours d'une semaine à l'Université Royal Roads, située à Victoria, intitulé *Creative Leadership For Health Care Administrators*. Au début de la semaine, dans le cadre d'une session interactive, on nous a demandé de marcher dans une grande salle de conférences, de nous arrêter et de nous présenter à un(e) autre participant(e) que nous ne connaissions pas. L'exercice exigeait que nous passions le quart d'heure suivant à dire à l'inconnu(e) en face de nous quelles étaient, selon nous, les trois choses les plus importantes que nous aimerions accomplir ou voir se réaliser avant notre mort. Je vous assure que la lecture des instructions a été suivie d'un silence stupéfait. J'ai entendu bien des rires jaunes qui se sont transformés en chuchotements avant de céder la place aux larmes, alors que nous examinions en profondeur notre propre mort et la signification de la vie. J'ai su instantanément quelles étaient ces trois choses importantes bien que je n'y aie jamais vraiment pensé auparavant.

Pour celles d'entre vous qui me connaissent, mon premier espoir ne vous surprendra pas car je voulais

devenir grand-mère! Et je dois vous dire que ce vœu ne s'est pas encore réalisé et qu'apparemment, il n'est pas près de l'être. En revanche, ma petite sœur m'a remplie de joie en donnant naissance à son premier enfant, une fille qui est née le jour de mes 50 ans! Je vais donc être tante et pour ainsi dire grand-mère. Mon deuxième espoir est de développer une certaine paix intérieure, une tâche des plus difficiles dont je ne verrai jamais la fin, mais je fais de réels progrès dans mon cheminement spirituel.

Mon troisième espoir était que je tenais absolument à offrir quelque chose en retour à la collectivité et à la profession infirmière qui m'avaient tant donné. Les soins infirmiers ont façonné l'évolution de ma vie et la personne que je suis devenue. Une fois le cours terminé, je me suis engagée à rechercher des possibilités de service au sein de l'ACIO qui me permettraient de contribuer, à mon tour, à l'avancement des soins infirmiers. J'espère que mes quatre années de service au sein du Conseil national, les deux dernières à titre de présidente, m'ont permis de réaliser au moins une partie de mon vœu. Vous ne serez pas étonnées si je vous dit que c'est certainement moi qui y ait le plus gagné grâce à l'appui des membres de l'association et de celui du Conseil national et du Comité exécutif, au cours des quatre dernières années. Le grand nombre de gentilleses, les centaines de messages électroniques, les "cacardements" d'encouragement m'ont été d'un grand soutien durant les deux dernières années remplies de défis et même parfois difficiles. Les années consacrées au Conseil national de

l'ACIO ont accru mon engagement vis-à-vis de l'excellence dans les soins infirmiers et m'ont permis de rencontrer tant d'infirmières dévouées et bienveillantes des quatre coins du pays. Je comprends beaucoup mieux les difficultés que connaît notre nation en matière d'unité lorsqu'il s'agit de respecter des différences bien réelles et uniques. En guise de conclusion, j'applaudis mes collègues du Québec non seulement pour la merveilleuse manifestation qu'elles ont préparée pour nous cette semaine mais aussi pour le soutien continu et indéfectible qu'elles apportent à l'ACIO.

Je quitte maintenant la tête du peloton et j'en confie la direction à ma collègue Esther Green qui a été un véritable mentor pour moi et qui, je le sais, nous fournira le leadership nécessaire et le courage d'emprunter de nouveaux chemins. Du fond du cœur, merci à toutes de m'avoir donné l'occasion de vous représenter. Au cours des prochains jours, racontez-vous aux infirmières parmi lesquelles vous comptez des amies, des mentors et des collègues. Prenez le temps de réfléchir aux trois choses importantes que vous aimeriez peut-être accomplir durant la vie si précieuse qui vous a été donnée. Merci.

Carolyn Tayler,
ancienne présidente de l'ACIO

Référence

Goertz Koerner, J., & Schmidt Bunkers, S. (1992). Transformational leadership: The power of symbol. *Nursing Administration Quarterly*, 17(1), 1-9.

CANO is on the web!!!

In search of CANO's web pages? Here's how to find us:

- go to the Canadian Oncology Society's (COS) website, found at www.cos.ca
- when the COS home page appears, click on the number 5 in lower portion of left-hand side of screen; this will take you to the next screen
- on the left-hand side of the new screen, click on "Affiliated Societies"
- members of COS will appear. Scroll down until you find CANO
- click on CANO's name
- you will arrive at CANO's home page where the philosophy, mission, and goals and objectives are easily viewed
- CANO's home page also allows you to obtain a membership form and/or obtain access to CANO's secure web pages
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Purdue Pharma Ad

This column will highlight education and practice issues for research and research application. Our aim is to increase awareness and comfort with research and to demonstrate that research can be user-friendly.

Issues involved in the accrual of respondents

by Priscilla M. Koop

The accrual of research respondents in sufficient numbers and in a timely manner is a crucial factor in the success of a research project (Steger, 1997). Indeed, it is my experience (in my own research and that of my graduate students), that the process of accrual is often fraught with unexpected problems. One of the reasons for these difficulties is the lack of guidance regarding the pitfalls and their solutions in the education of nurse researchers. Wray and Gates (1996) state that the issues of accrual of participants for nursing research is a relatively new subject of study. The purpose of this column is to raise some of the issues involved in accrual or recruitment of research respondents and to present some ways of facilitating the process.

First, I'd like to define the relevant research terms that will be used in this column. Research respondents are sometimes referred to as "subjects," "study participants," or "informants." These are the people who provide the "data" (or information) for the research (Polit & Hungler, 1999). Together, these respondents comprise the study sample. The sample should be representative of the population to which the study is expected to generalize its findings (in quantitative research). In qualitative research, the informants are purposely selected for their ability to demonstrate the full range of attributes of the concept (or phenomenon) being studied. For the purpose of this column, "accrual" or "recruitment of respondents" will refer to the process of inviting potential research respondents to participate in the research, informing them of the purpose and process of the research project, and getting informed consent to participate.

Vulnerable populations

Cancer nursing research, by its very nature, involves vulnerable populations. Patients and families experience tremendous stress as a result of the disease, the treatments, and the effects of both on personal and family

lives. These stresses are increased at the time points that much of cancer nursing research takes place - at diagnosis, recurrence, or during the terminal phase. Pediatric, adolescent, and elderly cancer patients, in addition experience stresses related to the interplay between their cancer and their developmental status. This vulnerability presents challenges to clinicians and researchers alike. Nurses and physicians often feel very protective of their patients and are reluctant to expose them to unnecessary stressors. Having a research assistant approach particularly vulnerable patients to invite them to participate in research is seen by some clinicians as an unnecessary stressor. The unanticipated result is that patients who might have wished to participate in the research are not given the opportunity to do so. Researchers commonly encounter "gate keeping" by nurses, physicians, and family caregivers who are trying to protect these very vulnerable people in their care (Dowling & Wiener, 1997; Sque, 2000).

The increased focus on evidence-based practice suggests that we need to develop our knowledge base regarding the care of all our patients, and some research questions can only be answered by vulnerable respondents themselves. Moore and Miller (1999) make an excellent argument for the participation in research by members of vulnerable populations, "Only when vulnerable groups receive the appropriate research attention are the standards of their care and their quality of life enhanced" (p.1034). To develop this knowledge base while being sensitive to the vulnerability of patients is of paramount importance.

Researchers must attend to the vulnerability of cancer patients and their family members by designing their research to minimize the burden of participation. Meeting patients and family members at a time and place of their own choosing, using the minimum number of questions in a survey instrument, pacing interviews, offering to conduct interviews over several short periods,

offering to take breaks when energy lags, making sure that support persons (professional and lay) are available, should they be needed - all can reduce the negative impacts of research. By assuring clinicians, patients, and family members of these adjustments, researchers can demonstrate that patients' and family members' vulnerability will be treated with sensitivity and respect. As a result, trust is enhanced and the accrual process is facilitated.

Collaboration with clinicians

Nurses and physicians are in a position to facilitate or hamper accrual of respondents. Patients trust their professional caregivers and value their views. Physician recommendations for participation in clinical trials have been found to increase the likelihood of patient participation in clinical trials by a factor of 13 (Kinney, Richards, Vernon, & Vogel, 1998). Staff nurses are in a unique position to facilitate the success of trials (Edens & Safcsak, 1998; Sadler, Lantz, Fullerton, & Dault, 1999). Staff nurses are responsible for promoting trials, recruiting patients, educating them and their families, and supporting patients throughout the trial. These responsibilities require that nurses understand the various trials (and other types of research) going on in their clinical setting. They need to understand and value what clinical research can do for the well-being of patients and family members. They need to value evidence-based practice and they need to have an understanding of the research process itself. There are a number of strategies which researchers can use to involve nurses and physicians in the research process.

Nurses who work with patients on a daily basis often have ideas on how to facilitate the research process. Researchers should take advantage of this expertise and should keep in touch with the nurses to detect problems early and to find ways of solving them. McGuire et al. (2000) invited nurses to participate in decision-making about selected aspects of the research methods, provided nurses with regular updates on the process of the research project, and generally interacted with them as colleagues. Several nurses were hired as part-time study personnel. While these efforts were not without problems, the authors maintain that they facilitated the research process, including accrual.

Besides involving nurses in the research process, researchers also need to recognize the degree to which the research may disrupt the daily activity on a unit. McGuire et al. (2000) consulted nurses and studied the daily routine on the units on which they planned to conduct their study. In that way, they were able to modify their intended design to minimize the interruption of routine clinical activities. Such actions can promote useful interactions between clinicians and researchers and, thus, facilitate the work of both groups. Clinicians are more likely to promote research projects which they understand, see as relevant, and which have been designed with respect for clinicians and patients alike.

Sensitivity to developmental, cultural, and demographic characteristics

Given the mandate of quantitative research to produce generalizable findings, samples should be representative of the population with respect to a range of variables, including age, gender, ethnicity, and socioeconomic status. Despite this mandate, study samples typically underrepresent women (Flaskerud & Nyamathi, 2000; Kelly & Cordell, 1996), members of ethnic minorities (Chapple, 1998; Flaskerud & Nyamathi, 2000; Homer, 1999; Naranjo & Dirksen, 1998; Outlaw, Bourjolly, & Barg, 2000), and members of lower socioeconomic groups (Kelly & Cordell, 1996). Children and adolescents represent ethical and legal challenges related to informed consent (Lamb, Puskar, & Tusaie-Mumford, 2001; Lowes, 1996; Miller, 2000). These challenges apply to patients with cognitive deficits as well.

Researchers may have to make special efforts to have a representative sample. Fitzgibbon and colleagues (1998) studied two culturally diverse groups of black Americans and found that different research methods worked for the two groups. Their study suggests that researchers need to understand the needs, experiences, and the total environment of the target group and that accrual strategies must take all of these factors into account. Kelly and Cordell (1996) developed strategies to successfully enroll women into clinical trials in which they were traditionally underrepresented. These strategies included the provision of child care, timing research participation with routine clinic visits, and the provision of travel vouchers and stipends. When attempting to attract an ethnically diverse sample, researchers need to take into account the values and behavioural norms of the target cultures. The availability of reliable and valid multilingual research instruments further enhances the generalizability of research findings with respect to ethnicity.

Predicting accrual difficulties and their solutions

Pilot studies are strongly recommended to predict difficulties with the research process, including those related to accrual. Once identified, many problems can be eliminated or reduced. Steger (1997) recommends keeping track of the recruitment plan to aid in subsequent research. The recruitment plan should be described in publications resulting from the research. In this way, the knowledge base of recruitment problems and solutions can grow.

In this column, I have outlined several of the common issues in accrual of patients for cancer nursing research projects. I have raised issues related to the vulnerability of our research participants, the relationships between researchers and clinicians, and sensitivity to developmental, cultural, and demographic characteristics of research participants. As researchers consider the issues and design research projects accordingly, the development of our knowledge base will be enhanced. ♦

About the author

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Effets d'une intervention éducative sur l'anxiété de la femme en attente d'une mastectomie

Par France Provençal Belleau,
Louise Hagan et Benoît Mâsse

Abstré

Le but de cette étude expérimentale était d'évaluer les effets d'une intervention éducative psychocognitive individualisée sur l'anxiété préopératoire des femmes en attente d'une mastectomie. Un total de 60 femmes âgées entre 27 et 65 ans furent randomisées dans deux groupes de 30 femmes. L'instrument utilisé, l'Inventaire d'Anxiété Situationnelle (IAS), a permis d'observer à l'aide d'une analyse de variance à mesures répétées, qu'immédiatement après les interventions éducatives (expérimentale et contrôle), il y avait une réduction significative ($p < 0,01$) de l'anxiété, le groupe expérimental produisant une réduction additionnelle de 4,83 ($p = 0,05$). La veille de la chirurgie, seule l'intervention éducative expérimentale procurait une réduction significative ($p = 0,03$) de l'anxiété, mais la différence de l'effet entre les deux interventions éducatives n'est pas significative. Ces résultats semblent donc supporter la théorie Stress, appraisal and coping de Lazarus et Folkman selon laquelle une action directe sur la perception cognitive peut influencer la perception de menace telle qu'évaluée par le niveau d'anxiété.

L'Institut National du Cancer du Canada (INCC, 2000) estime qu'une femme sur 9,5 serait atteinte du cancer du sein au cours de sa vie. Les taux canadiens de cancer du sein seraient parmi les plus élevés au monde (Gaudette, Silberberger, & Atwell, 1994). Dans la période 1975-1992, le taux brut de mortalité dû au cancer du sein chez la femme s'est accru de 69,6% au Québec (Beaupré, 1995). Le cancer du sein vient ainsi au premier rang des cancers affectant les femmes dans cette province canadienne (Beaupré; INCC).

Lorsqu'un cancer est diagnostiqué la femme doit avoir accès à des services hospitaliers médicaux et infirmiers de qualité et ce, dans un contexte où, au Québec, le virage ambulatoire s'effectue très rapidement, bouleversant les pratiques professionnelles et les relations avec les patients (MSSS, 1996). Un des impacts de ce changement organisationnel est la réduction du temps d'exposition des femmes nécessitant une chirurgie aux interventions professionnelles des infirmières, notamment à l'intervention éducative visant à les préparer le plus adéquatement possible à cette chirurgie.

Le problème

La découverte du cancer et l'attente d'une mastectomie génèrent habituellement une grande anxiété (Northouse, 1989; Wainstock, 1991). Cette anxiété est la manifestation de peurs reliées à différents facteurs: la chirurgie elle-même, la douleur appréhendée, la mutilation, ou l'atteinte de l'image corporelle, l'étendue du cancer, la mort, la perte de l'attrait sexuel, et la perte de contrôle (Ali & Khalil, 1991; Lierman, 1984; Northouse; Reaby, Hort, & Vandervord, 1994; Royak-Schaler, 1992; Wainstock). Cette anxiété affecte à divers degrés la capacité de la femme à recevoir et à retenir les informations fournies lors de l'enseignement préopératoire (Haines, 1992; Lamarche, 1993; Oberle, Allen, & Lynkowski, 1994; Ruzicki, 1989; Young, De Guzman, Matis, & McClure, 1994).

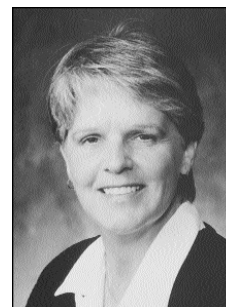
L'information adéquate et le soutien émotionnel sont alors des moyens susceptibles d'accroître le sentiment de contrôle nécessaire à la réduction de l'anxiété et conséquemment à l'adaptation au stress que représente la mastectomie (Palsson & Norberg, 1995).

Les contenus enseignés aux femmes sont le plus souvent standardisés. Ils ne sont donc pas nécessairement spécifiquement et directement reliés aux besoins perçus par les femmes elles-mêmes à ce moment de l'épisode de soin. Ces contenus concernent le plus souvent des aspects techniques (préparation physique à la chirurgie, sensations physiques attendues, exercices respiratoires, et habiletés motrices à acquérir). L'expression des émotions et l'écoute active des craintes ou des inquiétudes ne font pas prioritairement et systématiquement partie des interventions éducatives même si on sait par ailleurs qu'une telle approche peut potentiellement avoir des effets positifs sur la réduction de l'anxiété (Hathaway, 1986; Richardson & O'Sullivan, 1991).

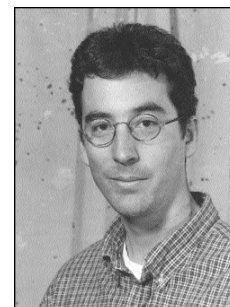
Le but de cette étude est donc d'évaluer les effets d'une intervention éducative psychocognitive individualisée sur l'anxiété des femmes en attente d'une mastectomie.



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Cadre théorique

Cette étude est basée sur la théorie de l'adaptation au stress de Lazarus et Folkman (1984). Cette théorie explique comment un individu devant une situation stressante procède à une évaluation cognitive (primaire, secondaire, et réévaluation) et fait face au problème en adoptant diverses stratégies adaptatives. Appliquée au contexte de la présente étude, la théorie de Lazarus et Folkman guide l'identification des facteurs perçus par les femmes comme étant des éléments de menace à leur intégrité physique, psychologique, et sociale et d'orienter en priorité les interventions éducatives vers ces facteurs stressants. Les interventions éducatives se veulent une ressource externe et ainsi une aide à l'adaptation des femmes en fournissant des réponses à la recherche d'informations par les femmes. Ces interventions peuvent modifier l'évaluation cognitive des événements perçus comme étant stressants et en conséquence réduire l'anxiété situationnelle leur étant reliée.

L'hypothèse de recherche est la suivante

Il y aura une plus grande réduction du degré d'anxiété chez les femmes ayant reçu une intervention éducative psychocognitive individualisée que chez les femmes ayant reçu l'intervention éducative de routine et ce, immédiatement après l'intervention éducative et la veille de la chirurgie.

Méthodologie

Devis de l'étude

Il s'agit d'une étude expérimentale pré-test/post-test.

Population et échantillon

La population à l'étude était constituée de femmes en provenance de l'est du Québec ayant reçu un diagnostic de cancer du sein et devant subir une chirurgie (mastectomie simple ou segmentaire avec ou sans évidemment ganglionnaire ou d'une mastectomie radicale modifiée). Elles devaient être âgées entre 21 à 65 ans et être capables de parler et lire le français. Les critères d'exclusion étaient la prise d'une médication anxiolytique sur une base régulière ou un suivi en psychiatrie en raison du biais que pourraient apporter ces conditions à la mesure de l'anxiété situationnelle chez cette clientèle.

Le recrutement des femmes a été réalisé dans un centre hospitalier de courte durée de la région de Québec dans la période du 28 septembre au 18 décembre 1998. Un total de 64 femmes ont été sélectionnées et 60 d'entre elles ont accepté de participer à l'étude. Trois femmes refusèrent en raison d'un manque de temps, de fatigue, et de désintéressement à remplir des questionnaires et une femme se retira en cours d'étude. Les femmes étaient réparties de manière aléatoire soit au groupe expérimental (E) ou soit au groupe contrôle (C) à l'aide d'une table des lettres alphabétiques. Dans les deux groupes, les femmes pouvaient être accompagnées d'une personne significative ou d'un proche si elles le désiraient.

Les variables de l'étude

La variable indépendante

L'approche éducative psychocognitive individualisée constituait la variable indépendante de l'étude. Elle a été définie comme étant la combinaison de l'approche psychothérapeutique et de l'approche cognitive. La dimension psychothérapeutique de l'intervention éducative expérimentale consistait à explorer et à soutenir systématiquement l'expression des sentiments et des émotions de la femme concernant la chirurgie, le diagnostic de cancer, et la relation avec le conjoint ou tous autres aspects constituant une préoccupation ou une source d'anxiété pour la femme. Elle permettait également d'explorer les stratégies adaptatives utilisées

par la femme et encourageait la recherche d'informations. Tout le temps requis était alors alloué à la femme afin qu'elle puisse pleinement exprimer ce qu'elle ressentait au moment de la rencontre et poser toutes les questions souhaitées. Au besoin, on lui offrait quelques minutes de relaxation (ex. respiration diaphragmatique contrôlée) pour calmer l'anxiété. Lors de l'expression des émotions (ex. pleurer) le toucher pouvait constituer une forme de soutien. La dimension cognitive de l'intervention éducative consistait à répondre en priorité aux besoins spécifiques d'informations exprimés par les femmes. On s'assurait alors d'un niveau minimal d'apprentissage soit l'acquisition et la compréhension des connaissances transmises en réponse aux besoins perçus par la femme elle-même et par l'infirmière.

Les outils d'enseignement utilisés étaient des cartes anatomiques, du matériel de démonstration, une brochure d'information concernant la chirurgie, et une vidéo sur le séjour au bloc opératoire.

Cette intervention expérimentale était comparée à l'intervention éducative habituelle plutôt orientée vers une approche cognitive plus directive basée principalement sur un enseignement plus standardisé couvrant toutes les informations des périodes pré, per, et postopératoires reliées à la mastectomie. L'intervention éducative habituelle pouvait aussi à l'occasion faire appel à l'écoute active et au soutien psychologique mais n'accordait pas systématiquement une priorité à l'expression des menaces perçues par les femmes et des sentiments et des émotions reliés.

La variable dépendante

Le degré d'anxiété situationnelle constituait la variable dépendante principale de l'étude.

Instruments de mesure et collecte des données

Les données ont été recueillies à l'aide de questionnaires auto-administrés complétés en trois temps: pré-intervention éducative (environ 14 à 19 jours avant la chirurgie), post-intervention éducative (immédiatement après l'intervention éducative, environ 14 à 19 jours avant la chirurgie), et la veille de la chirurgie (un jour avant la chirurgie). Un premier questionnaire était complété dès l'adhésion à l'étude. Il comportait les variables sociodémographiques, les variables reliées à l'histoire de la maladie, à l'existence d'un confident ou à des délais (délai diagnostic - intervention éducative et délai intervention éducative - chirurgie), ainsi que la mesure de l'anxiété situationnelle préopératoire. Le deuxième et le troisième questionnaires mesuraient à nouveau le degré d'anxiété.

L'Inventaire d'Anxiété Situationnelle (IAS) fut l'instrument utilisé pour mesurer le niveau d'anxiété préopératoire de la femme en attente d'une mastectomie avant et après l'intervention éducative, ainsi que la veille de la chirurgie. Le IAS est l'adaptation canadienne française d'un des deux questionnaires de la forme révisée du State-Trait Anxiety Inventory - Form Y (STAI-Y) de Spielberger (1983) traduite par Gauthier et Bouchard (1993).

Le IAS se présente sous la forme d'un questionnaire auto-administré de 20 phrases lesquelles évaluent l'état émotionnel actuel du sujet. Le répondant doit indiquer l'intensité de ses sentiments, sur une échelle de type Likert à quatre points, variant entre 1, «pas du tout» et 4, «beaucoup.» La répartition des énoncés manifestant la présence ou l'absence d'états émotifs déplaisants est égale, soit de 10 énoncés chacun (Bouchard, 1990). Les cotes peuvent varier de 20 à 80. Les cotes faibles reflètent le calme et la détente, les cotes moyennes des niveaux modérés de tension, et d'appréhension tandis que les cotes élevées correspondent à une grande peur, de l'appréhension, et de l'affolement (Bouchard). Les résultats de la présente étude auprès de 60 sujets révèlent une bonne homogénéité des items (Alpha de Cronbach=0,95).

Résultats

Le profil des répondantes

Il n'existe aucune différence statistique au niveau des caractéristiques sociodémographiques du groupe expérimental (intervention psychocognitive individualisée) et du groupe contrôle (intervention standard). L'âge des 30 femmes du groupe contrôle variait entre 36 et 64 ans (M: 51,50; Ét: 7,61) alors que celui des 30 femmes du groupe expérimental variait de 27 à 65 ans (M: 52,17; Ét: 9,00). Il y avait par ailleurs, une différence significative quant à la durée de l'intervention éducative: l'intervention éducative du groupe expérimental (M: 78,50 min.; Ét: 21,38) étant plus longue ($p < 0,01$) que celle du groupe contrôle (M: 50,93 min.; Ét: 16,97). Une différence significative ($X^2 = 4,80$; $df = 1$; $p = 0,03$) fut notée au niveau de la fréquence de la référence psychosociale (travailleuses sociales intervenant auprès des femmes référées): les femmes du groupe expérimental (46,7%) ayant été plus nombreuses à être référées que celles du groupe contrôle (20%).

L'anxiété préopératoire

Le niveau d'anxiété préopératoire a été mesuré avant l'intervention éducative, immédiatement après et la veille de la chirurgie chez les deux groupes (voir tableau 1). Aucune différence significative ($t = 1,57$; $df = 58$; $p = 0,12$) n'était présente entre les deux groupes avant l'intervention éducative.

Afin de vérifier l'efficacité de l'intervention éducative correspondante, une analyse de variance à mesures répétées a été effectuée à l'aide de la procédure PROC MIXED de SAS 6,12. Deux variables réponses sont présentées au tableau 2, une première représentant l'effet immédiatement après l'intervention éducative et l'autre, l'effet juste avant la chirurgie (veille de la chirurgie). Une valeur positive indique une réduction d'anxiété. On constate qu'immédiatement après l'intervention éducative, les deux types d'interventions éducatives procurent une réduction significative de l'anxiété, l'intervention éducative du groupe expérimental procurant une réduction additionnelle, significative, de l'anxiété de 4,83 par rapport à l'intervention éducative du groupe contrôle (10,53 versus 5,70).

De plus, seule l'intervention éducative du groupe expérimental procure également une réduction significative de l'anxiété jusqu'au moment de la veille de la chirurgie. Par ailleurs, il n'y a pas de différence significative de l'efficacité de l'intervention éducative la veille de la chirurgie entre les deux groupes.

Les résultats des tests de corrélation de rang de Spearman et l'analyse de variance démontrent qu'aucune des caractéristiques sociodémographiques, reliées à l'histoire de la maladie, à

l'existence d'un confident ou contextuelles n'est reliée au niveau d'anxiété avant l'intervention éducative.

Nous avons vérifié si l'efficacité des interventions éducatives (expérimentale et contrôle) était reliée aux caractéristiques des répondantes. Par l'analyse de variance, nous avons vérifié s'il y avait homogénéité de l'efficacité de l'intervention éducative dans les différentes catégories du statut civil (ex. célibataire, mariée/union de fait, et séparée/veuve) et du niveau de scolarité.

Nous avons observé dans le groupe expérimental que le fait que la femme soit accompagnée lors de l'intervention éducative semble relié à l'efficacité de l'intervention éducative immédiatement après l'intervention éducative ($rr = 0,43$; $p = 0,02$) et la veille de la chirurgie ($rr = 0,43$; $p = 0,02$). Ces corrélations positives, mais faibles, signifient que l'intervention éducative semble plus efficace lorsque la femme est accompagnée pendant l'intervention éducative. On observe également une corrélation négative ($rr = -0,41$; $p = 0,03$) entre le fait d'avoir une histoire familiale de cancer du sein et l'efficacité de l'intervention éducative. On observe une interaction significative ($p = 0,02$) qui montre qu'une différence d'efficacité des interventions est attribuable à différents statuts. En effet, les femmes mariées ou vivant en union de fait avaient un degré moindre d'anxiété et ce, immédiatement après l'intervention éducative expérimentale.

Dans le groupe contrôle, le fait d'avoir déjà eu une chirurgie pour cancer du sein semble relié ($rr = -0,38$; $p = 0,04$) à l'efficacité de l'intervention éducative la veille de la chirurgie tout comme le délai d'attente (intervention éducative-chirurgie) ($rr = -0,40$; $p = 0,03$). Il semble donc que plus l'attente entre l'intervention éducative et la chirurgie augmente, moins l'efficacité de l'intervention éducative persiste la veille de la chirurgie. Cependant, le nombre de sujets ($n = 5$) ayant déjà eu une chirurgie pour cancer du sein est trop petit pour pouvoir conclure qu'il y a une relation. Une étude avec un échantillon plus grand pourrait peut-être permettre de confirmer la relation.

De même, tant dans le groupe expérimental ($rr = 0,41$; $p = 0,03$) que dans le groupe contrôle ($rr = 0,42$; $p = 0,02$), nous avons observé qu'il existe une association entre le niveau d'anxiété la

Tableau 1: Niveaux d'anxiété préopératoire aux trois temps de mesure

Anxiété	Groupe E (n = 30) Intervention individualisée		Groupe C (n = 30) Intervention standard	
	Moyenne	Écart-type	Moyenne	Écart-type
Anxiété avant l'intervention éducative: IAS #1	52,00	15,32	46,33	12,58
Anxiété immédiatement après l'intervention éducative: IAS #2	41,47	12,18	40,63	11,98
Anxiété la veille de la chirurgie: IAS #3	47,03	14,45	44,90	11,76

Tableau 2: Efficacité de l'intervention éducative sur la réduction de l'anxiété immédiatement après l'intervention éducative et la veille de la chirurgie

Efficacité	Groupe E (n = 30) Intervention individualisée		Groupe C (n = 30) Intervention standard		Différence entre les deux groupes	
	Réd. anx.	valeur-p*	Réd. anx.	valeur-p*		
Effet immédiatement après l'intervention éducative: IAS #1 - IAS #2	10,53	<0,01	5,70	<0,01	4,83	0,05
Effet la veille de la chirurgie: IAS #1 - IAS #3	4,84	0,03	1,43	0,51	3,41	0,27

veille de la chirurgie et le fait d'avoir été référée à une ressource psychosociale (travailleuse sociale) en fin d'intervention éducative. En effet, les femmes (n=20) qui ont été référées à une ressource psychosociale avaient une baisse du niveau d'anxiété la veille de la chirurgie de 11,08 (Ét: 13,03) dans le groupe expérimental (n=14) et de 11,00 (Ét: 6,16) dans le groupe contrôle (n=6) comparativement au niveau d'anxiété avant l'intervention éducative. La femme qui signifiait vouloir rencontrer une ressource psychosociale était référée suite à l'intervention éducative (service offert à toutes les femmes en attente d'une mastectomie). Le contact avec la travailleuse sociale pouvait se faire avant ou après la chirurgie selon le désir de la femme. Les analyses n'ont cependant pas été faites en fonction du contact préopératoire (rencontrée ou non), du type (contact téléphonique, entrevue, etc.), et du nombre d'interventions mais plutôt en fonction de la référence psychosociale (référée / non référée).

Discussion

L'intervention additionnelle de la ressource psychosociale (travailleuses sociales à qui certaines femmes étaient référées) avant la chirurgie a potentiellement introduit un biais dans les résultats de la troisième mesure de l'anxiété préopératoire soit celle la veille de la chirurgie. Il aurait fallu contrôler cette variable (référence psychosociale) en faisant les analyses spécifiques (contactée avant chirurgie/non contactée) afin d'évaluer l'impact sur la troisième mesure. De plus, comme le service était offert par deux travailleuses sociales, il aurait fallu s'assurer de l'uniformité de l'intervention psychosociale. Ceci représente donc une limite à cette étude.

Le degré d'anxiété dans la population en général évalué par le State-Trait Anxiety Inventory (STAI). Spielberger (1983) est établi selon la catégorie d'âge et le sexe. Pour les femmes entre 50 et 54 ans, le niveau d'anxiété moyen est de 32,60 (Ét: 7,30). Un écart-type plus haut que la moyenne indique un niveau d'anxiété élevé (39,90). Ce qui signifie que certaines femmes ayant participé à la présente étude (âge moyen de 52 ans) avaient un niveau d'anxiété élevé avant l'intervention éducative puisque leur niveau d'anxiété était plus de 39,90, soit un écart-type plus haut que la moyenne normative avec des moyennes de 46,33 (Ét: 12,58) et 52,00 (Ét: 15,32) dans les groupes contrôle et expérimental. Ainsi, la perception de menace liée au cancer du sein et à la chirurgie semble donc bien réelle.

L'intervention éducative psychocognitive individualisée visait à réduire le niveau d'anxiété par une influence directe sur la perception de menace et la satisfaction du besoin de connaissances reliées à l'événement stressant. Les résultats de l'étude démontrent qu'immédiatement après l'intervention éducative, on observe que les deux types d'interventions éducatives (expérimentale et contrôle) entraînent une diminution significative du niveau d'anxiété.

Bien que peu d'études aient évalué l'effet d'une intervention éducative individuelle réalisée par une infirmière auprès d'une clientèle en attente d'une chirurgie, les résultats de la présente étude semblent converger avec ceux de l'étude de Shimko (1981) réalisée auprès de 81 clients en attente d'une neurochirurgie où on a observé une diminution du niveau d'anxiété d'un score moyen de 6,0 immédiatement après une intervention éducative individuelle ou en petits groupes axée sur les aspects cognitifs et psychomoteurs. Ces résultats suggèrent donc que le fait de donner uniquement de l'information est suffisant pour réduire le niveau d'anxiété immédiatement après l'intervention éducative.

L'étude de Richardson et O'Sullivan (1991) avec devis quasi-expérimental auprès de 60 clients en attente d'une chirurgie élective démontrait que le groupe ayant reçu une intervention éducative individuelle la veille de la chirurgie avait un niveau d'anxiété

significativement ($F(1,58)=4,97$; $p < 0,05$) plus bas ($M: 40,43$; $Ét: 9,76$) que le groupe n'ayant reçu aucune intervention éducative ($M: 47,16$; $Ét: 14,97$). L'intervention éducative apportait du soutien au client et le contenu était orienté vers les peurs ou craintes et questions en relation avec la chirurgie.

Cliniquement, avec le IAS, une diminution du degré d'anxiété de 5,7 signifie que deux énoncés sur 20 (soit 10% des énoncés) ont été réduits de 2 et qu'un autre a baissé de 1 ou que cinq énoncés (soit 25% des énoncés) ont été réduits de 1, ce qui pourrait être considéré comme signifiant. Une diminution du degré d'anxiété de 10,53, représente 5 énoncés sur 20 (soit 25 % des énoncés) ayant subi une baisse de 2 sur l'échelle de type Likert ou 10 énoncés (soit 50% des énoncés) ayant baissé de 1 par exemple, ce qui représente une réduction additionnelle signifiante. Une réduction additionnelle du degré d'anxiété de 4,83 est donc signifiante pour la femme en attente d'une mastectomie.

Dans le groupe contrôle, l'intervention éducative débutait par le dossier préadmission (vérification de l'exécution des examens diagnostiques et des consultations préopératoires faits et collecte de données habituelles). Les craintes ou inquiétudes en regard de la chirurgie, l'hospitalisation ou le retour à domicile étaient vérifiées mais on n'explorait pas en profondeur les craintes ou les peurs vécues suite au diagnostic de cancer et à l'annonce d'une mastectomie, ni la relation avec le conjoint et la famille depuis le diagnostic. Les stratégies d'adaptation utilisées par les femmes pour résoudre un problème et le réseau de soutien existant représentaient également des éléments explorés avec la femme mais n'occupaient pas une place prépondérante. Le matériel d'enseignement utilisé et le contenu de l'information en vue de préparer la femme à la chirurgie et aux soins à se donner étaient cependant les mêmes dans les deux types d'interventions éducatives et ces aspects similaires ont probablement contribué à réduire l'anxiété préopératoire. Ceci pourrait également expliquer pourquoi la différence entre les deux interventions éducatives n'est pas plus grande que 4,83.

Il est possible que la durée de l'intervention éducative du groupe expérimental, significativement plus grande ($p < 0,01$) que celle pour le groupe contrôle ait également contribué à un effet plus marqué sur la réduction du niveau d'anxiété dans ce groupe. Le temps plus long d'écoute active et d'expression des émotions peut en effet potentiellement contribuer à réduire davantage l'anxiété en permettant aux femmes de communiquer l'ensemble de leurs préoccupations et des questions reliées à la chirurgie et au diagnostic de cancer du sein et de recevoir les réponses attendues.

Lorsque le niveau d'anxiété est élevé, ce qui est le cas pour les femmes de la présente étude, Lazarus et Folkman (1984) précisent que l'individu utilisera la stratégie d'adaptation orientée vers les émotions avant même que la stratégie d'adaptation orientée vers le problème puisse être initiée. Le fait que l'intervention éducative expérimentale soit axée sur l'expression des sentiments, des émotions et sur le soutien peut avoir contribué à un effet plus marqué sur la réduction de l'anxiété, l'approche utilisée répondant davantage à une stratégie orientée vers les émotions. Nous pouvons donc croire que cette diminution importante de l'anxiété dans le groupe expérimental soit largement attribuable à la nature même de l'intervention expérimentale.

Le contexte de l'intervention éducative expérimentale, soit le fait que les rencontres aient eu lieu dans un local d'enseignement différent (salle conviviale et intime) de celui utilisé pour le groupe contrôle a peut-être aussi contribué à une meilleure disposition de la femme et influencé à la baisse son niveau d'anxiété.

Dans le groupe expérimental, une partie de l'effet de l'intervention éducative sur la réduction de l'anxiété semble persister jusqu'à la veille de la chirurgie (écart de 4,84; $p=0,03$). La différence de l'effet des deux types d'interventions éducatives au moment de la veille de la chirurgie n'est pas significative ($p=0,27$). On ne peut donc prétendre à une efficacité accrue de l'intervention expérimentale.

Dans le groupe expérimental, l'efficacité de l'intervention éducative semble associée au fait d'être accompagnée lors de l'intervention éducative ($rr=0,43$; $p=0,02$). L'approche psychocognitive individualisée permettait à la femme d'être accompagnée. Lors de l'intervention éducative, la participation et le soutien de la personne significative (amie, conjoint, ou proche) étaient sollicités et encouragés. Ceci a pu contribuer à réduire davantage le niveau d'anxiété. Les femmes étaient par ailleurs invitées à être accompagnées lors de l'intervention éducative tant dans le groupe expérimental que dans le groupe contrôle. Il n'y avait cependant pas de stratégie systématique de sollicitation de la participation et du soutien des personnes accompagnant la femme dans l'intervention éducative du groupe contrôle.

Conclusion

L'infirmière occupe une place privilégiée pour aider et soutenir la femme en attente d'une mastectomie. Il semble qu'une intervention éducative dans la période préopératoire puisse contribuer à réduire l'anxiété des femmes en attente d'une mastectomie. Une intervention éducative d'orientation psychocognitive semble également contribuer à réduire davantage cette anxiété.

Les résultats de cette étude confirment l'importance de mieux planifier et de mieux concevoir les interventions éducatives auprès de cette clientèle. La présente étude a notamment démontré l'importance d'orienter les interventions éducatives non seulement sur les aspects cognitifs reliés à la chirurgie, mais également sur les

aspects psychologiques (expression des peurs, craintes, menaces, appréhensions) reliés à la chirurgie et au diagnostic de cancer plus particulièrement. Il importe donc de plus en plus, malgré des contextes parfois peu favorables à l'humanisation et à l'individualisation des interventions des infirmières, que les efforts soient soutenus et encouragés pour améliorer la qualité de l'enseignement aux femmes en attente d'une mastectomie. Il serait peut-être aussi utile d'envisager une forme de suivi auprès des femmes entre le moment de l'intervention éducative jusqu'à la veille de la chirurgie afin de favoriser le maintien d'un niveau d'anxiété acceptable pour une qualité de vie optimale dans ce difficile épisode du traitement du cancer du sein. Un tel suivi, téléphonique ou autre forme, pourrait faire l'objet d'une recherche ultérieure et permettrait ainsi de déterminer si les pratiques cliniques devraient être modifiées afin que la femme puisse bénéficier d'une intervention éducative visant à réduire son anxiété jusqu'à la veille de la chirurgie.

D'autres études devraient aussi permettre de mieux cerner la spécificité des approches éducatives utilisées lors de l'enseignement préopératoire afin de mieux évaluer la contribution des diverses composantes de l'intervention évaluée. Il serait également nécessaire de mieux contrôler l'apport de certaines variables confondantes tel le recours à d'autres ressources d'aide psychosociale lorsqu'on souhaite notamment mesurer la persistance de la réduction du niveau d'anxiété jusqu'à la veille de la chirurgie. De la même façon, il faudrait s'assurer que le contexte physique de l'intervention éducative soit identique dans les groupes comparés.

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Effects of an educational intervention on the anxiety of women awaiting mastectomies

By France Provençal Belleau, Louise Hagan, and Benoît Mâsse

Abstract

The purpose of this experimental study was to assess the effects of an individualized psychocognitive educational intervention on pre-operative anxiety in women awaiting mastectomies. A total of 60 women aged between 27 and 65 years were randomly distributed to two groups of 30 participants. Using the Situational Anxiety Inventory (IAS) along with repeated-measures variance analysis, it was noted that, immediately following the educational interventions (both experimental and control) there was a significant reduction ($p < 0.01$) of anxiety with the experimental group having an additional reduction of 4.83 ($p = 0.05$). The day before surgery, only the experimental educational intervention resulted in a significant reduction ($p = 0.03$) of anxiety, but the difference between the two educational interventions was not significant. These results appear to support Lazarus and Folkman's stress, appraisal and coping theory which states that direct action on cognitive perception can influence a feeling of threat as assessed through the level of anxiety.

The National Cancer Institute of Canada (NCIC, 2000) estimates that one in 9.5 women will develop breast cancer during her lifetime. Canadian breast cancer rates are said to be among the highest in the

world (Gaudette, Silberberger, & Atwell, 1994). During the 1975-1992 period, the crude mortality rate related to breast cancer in women increased by 69.6% in Quebec (Beaupré, 1995). Breast cancer ranks first among the cancers affecting women in this Canadian province (Beaupré; NCIC).

When cancer is diagnosed, women must have access to quality hospital medical and nursing services, but in Quebec, this is taking place in a context where the shift to ambulatory care is proceeding very fast, thus disturbing professional practices and relationships with patients (MSSS, 1996). One of the impacts of this organizational change has been a reduction of the time women requiring surgery are exposed to nurses' professional interventions, especially the educational intervention aimed at preparing them for this surgery in the best possible way.

The problem

A great deal of anxiety usually occurs with the discovery of cancer and the wait for a mastectomy (Northouse, 1989; Wainstock, 1991). This anxiety is the result of fears related to various factors: the surgery itself, apprehension of pain, mutilation, effects on body image, extent of cancer, death, loss of sexual attractiveness, and loss of control (Ali & Khalil, 1991; Lierman, 1984; Northouse; Reaby, Hort, & Vandervord, 1994; Royak-Schaler, 1992; Wainstock). In varying degrees, this anxiety affects the women's ability to receive and retain the information provided through pre-operative teaching (Haines, 1992; Lamarche, 1993; Oberle, Allen, & Lynkowski, 1994; Ruzicki, 1989; Young, De Guzman, Matis, & McClure, 1994).

The provision of adequate information and emotional support is an avenue that is likely to increase the sense of control required to reduce anxiety and consequently to cope with the stress associated with the mastectomy (Palsson & Norberg, 1995).

Most often the content taught to women is standardized. Thus it is not necessarily particular and directly related to the perceived needs of the women themselves at this episode of care. The content often deals with technical aspects (physical preparation for surgery, expected physical effects, respiratory exercises, and motor skills to be acquired). The expression of emotions and active listening of fears or concerns are not part of the systematic priorities of the educational interventions even when we know that such an approach can potentially have a positive impact in reducing anxiety (Hathaway, 1986; Richardson & O'Sullivan, 1991).

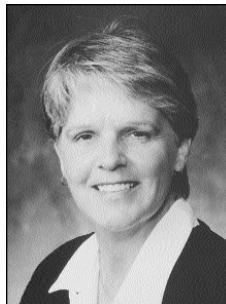
The purpose of this experimental study was to assess the effects of an individualized, psychocognitive, educational intervention on pre-operative anxiety in women awaiting mastectomies.

Theoretical framework

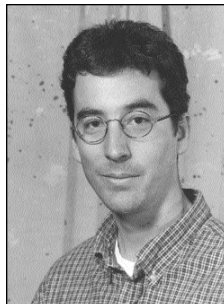
This study is based on Lazarus and Folkman's (1984) stress coping theory. This theory explains how an individual facing a stressful situation performs a cognitive assessment (primary, secondary, or reassessment) and deals with the problem using various coping strategies. As applied to the context of this study, Lazarus and Folkman's theory helps identify the factors perceived by women as threatening their physical, psychological, and social integrity and helps prioritize the educational interventions aimed at these stress factors. The educational interventions are meant to be an external resource and, thus, provide coping assistance to women by providing answers to their search for information. These interventions can change the cognitive assessment of events perceived as being stressful and, consequently, reduce the associated situational anxiety.



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The research hypothesis

That immediately after the educational intervention and on the day before surgery there will be a greater reduction in the anxiety level in women who participated in an individualized, psychocognitive, educational intervention than in women who only received the standard educational intervention.

Methodology

Study design

This is a pre-test/post-test experimental study.

Population and sample

The population in the study was composed of women from eastern Quebec who had been diagnosed with breast cancer and were scheduled to have surgery (simple mastectomy or segmentectomy with or without node dissection or modified radical mastectomy).

They had to be between the ages of 21 and 65, and able to read and speak French. Exclusion criteria were the taking of anxiolytic medication on a regular basis or a psychiatric follow-up because of the bias that these factors could have on the measurement of situational anxiety among these patients.

The women were recruited in an acute care hospital in the Quebec City area between September 28 and December 18, 1998. Sixty-four women were selected in total and 60 of them agreed to take part in the study. Three women refused due to lack of time, fatigue, or lack of interest in completing forms, and one woman dropped out during the study. Women were then randomly assigned to the experimental group (E) or control group (C) with the help of a table using alphabetical letters. In both groups, the participants could be accompanied by a significant other or a family member if so desired.

Study variables

Independent variable

The individualized, psychocognitive, educational approach was the study's independent variable. It was defined as a combination of both psychotherapeutic and cognitive approaches. The psychotherapeutic dimension of the experimental educational intervention involved exploring and systematically supporting each woman in the expression of her feelings and emotions about the surgery, cancer diagnosis, spousal relationship, or any other aspects that represented a concern or a source of anxiety. It also allowed for the exploration of the coping strategies used by the woman and encouraged information-seeking. At the meeting, each woman was given the necessary time to fully express what she was feeling at that time and to ask all the questions she wanted. When needed, the participant was offered a few minutes of relaxation (e.g. controlled diaphragmatic breathing) to alleviate anxiety. When emotions were expressed (e.g. crying) touching could represent a form of support. The cognitive dimension of the educational intervention was first meant to respond to the specific informational needs expressed by the participants. A minimum level of learning was thus ensured, i.e. the acquisition and understanding of information provided in response to the perceived needs of the woman herself and the nurse.

Teaching tools used were anatomical charts, demonstration material, an information brochure about the surgery, and a video on the stay in the operating area.

This experimental intervention was compared to the regular educational intervention which was oriented towards a more direct cognitive approach and based mainly on more standardized education covering information related to the pre-, peri-, and post-operative mastectomy periods. The regular educational intervention could also occasionally involve active listening and psychological support, but it did not systematically prioritize the women's expressions of perceived threats and their associated feelings and emotions.

Dependent variable

The main dependent variable in the study was the level of situational anxiety.

Measurement instruments and data collection

The data were collected by means of self-administered questionnaires completed at three different times: pre-educational intervention (about 14-19 days before the surgery), post-educational intervention (immediately after the educational intervention, about 14-19 days before surgery), and presurgery (the day before surgery). The first questionnaire was completed upon joining the study. It included sociodemographic variables, variables related to the history of the present illness, the existence of a confidante, and the wait times (time between diagnosis and the educational intervention and between the educational intervention and surgery), as well as measurement of pre-operative situational anxiety. The second and third questionnaires again measured the anxiety level.

The Situational Anxiety Inventory (IAS) was the instrument used to measure the pre-operative anxiety level in women awaiting mastectomies before and after the educational intervention, as well as on the day before surgery. The IAS is a French-Canadian adaptation of one of two questionnaires in the revised version of the State-Trait Anxiety Inventory - Form Y (STAI-Y) by Spielberger (1983) as translated by Gauthier and Bouchard (1993).

The IAS takes the form of a self-administered questionnaire composed of 20 sentences that assess the subject's current emotional state. The respondent is required to indicate the intensity of his/her feelings on a four-point Likert scale ranging from 1, "Not at all" to 4, "A lot". There is an equal distribution of statements (10 each) indicating the presence or absence of unpleasant emotional states (Bouchard, 1990). Ratings can vary between 20 and 80. Lower ratings reflect calm and relaxation, mid-range ratings correspond to moderate levels of stress and apprehension, while higher ratings indicate significant fear, apprehension, and panic (Bouchard). This study's results with 60 subjects reveal good homogeneity among the items (Cronbach's Alpha=0.95).

Results

Respondents' profile

There were no statistical differences in the sociodemographic characteristics between the experimental group (individualized psychocognitive intervention) and the control group (standard intervention). In the control group, the age of the 30 women varied between 36 and 64 (M 51.50; S.D. 7.61) while that of their counterparts in the experimental group varied from 27 to 65 (M 52.17; S.D. 9.00). There was, however, a significant difference in the length of the educational intervention: the educational intervention for the experimental group (M 78.50 min.; S.D. 21.38) was longer ($p < 0.01$) than that of the control group (M 50.93 min.; S.D. 16.97). A significant difference ($X^2 = 4.80$; $df=1$; $p=0.03$) was noted with regard to the frequency of psychosocial referrals (a social worker working with the referred women) as there were many more referrals for women in the experimental group (46.7%) than in the control group (20%).

Pre-operative anxiety

The pre-operative anxiety level was measured in both groups before the educational intervention, immediately after, and the day before surgery (see Table One). No significant difference was present between the two groups before the educational intervention ($t=1.57$; $df=58$; $p=0.12$).

In order to verify the effectiveness of the corresponding educational intervention, a repeated-measurement analysis of variance was done by means of the PROC MIXED procedure using SAS 6.12. Two measured variables are presented in Table Two, the first representing the effect immediately after the educational

intervention and the other, the effect just before surgery (on the day before). A positive value indicates reduced anxiety. One observes that immediately after the educational intervention both types of educational interventions resulted in significant anxiety reduction, with the experimental group's educational intervention showing a significant additional reduction of anxiety of 4.83 when compared to the control group's educational intervention (10.53 versus 5.70).

Moreover, only the experimental group's educational intervention resulted in significant anxiety reduction until the day before surgery. Otherwise, there was no significant difference between the two groups regarding the educational intervention's effectiveness the day before surgery.

The results of the Spearman rank correlation tests and variance analysis showed that none of the sociodemographic characteristics associated with the history of the present disease, the existence of a confidante, nor contextual characteristics were connected to the anxiety level before the educational intervention.

We checked to see if the effectiveness of the educational interventions (for both groups) was linked to the respondents' characteristics. Variance analysis allowed us to verify the homogeneity of the effectiveness of the educational intervention among the various categories of marital status (i.e. single, married/living common-law, separated/widowed) and education level.

In the experimental group we observed that when a woman was accompanied to the educational intervention, there seemed to be a link between that fact and the effectiveness of the educational intervention immediately after the educational intervention ($r^2=0.43$; $p=0.02$) and on the day before surgery ($r^2=0.43$; $p=0.02$). These positive correlations, while weak, mean that the educational intervention seems to be more effective when the woman is accompanied. We also noticed a negative correlation ($r^2=-0.41$; $p=0.03$) between having a family history of breast cancer and the effectiveness of the educational intervention. A significant response ($p=0.02$) was observed showing that a difference in the effectiveness of the interventions was related to differences in marital status. Indeed, married women or women in common-law relationships had a lower anxiety level immediately after the experimental educational intervention.

In the control group, previous surgery for breast cancer seemed to be linked ($r^2=-0.38$; $p=0.04$) to the effectiveness of the educational intervention on the day before surgery, as was the waiting period (educational intervention to surgery) ($r^2=-0.40$; $p=0.03$). It appeared that the longer the wait between educational intervention and surgery, the lower the effectiveness of the educational intervention on the day before surgery. However, the number of subjects ($n=5$) who had previous breast cancer surgery was too low to establish a conclusive relationship. A study with a larger sample could possibly confirm this relationship.

Also, in both the experimental ($r^2=0.41$; $p=0.03$) and control ($r^2=0.42$; $p=0.02$) groups, an association was observed between the anxiety level on the day before surgery and a referral to a psychosocial resource (social worker) at the end of the educational intervention. Indeed, women ($n=20$) who had been referred to a psychosocial resource had, on the day before surgery, a reduction of their anxiety level of 11.08 (S.D. 13.03) in the experimental group ($n=14$) and of 11.00 (S.D. 6.16) in the control group ($n=6$) when compared to their anxiety level before the educational intervention. The women who expressed the desire to meet with a psychosocial resource were referred after the educational intervention (this service was offered to all the women awaiting mastectomies). It was up to them whether they contacted the social worker before or after surgery. However, no analyses were done regarding pre-operative contact (whether seen or not), contact type (telephone, interview, etc.), and the number of interventions, but rather whether or not there was a psychosocial referral made (referred/non-referred).

Discussion

The additional intervention by the psychosocial resource (the social workers to whom some of the women were referred) before surgery potentially introduced a bias in the results for the third pre-operative anxiety measurement, i.e. on the day before surgery. This variable (psychosocial referral) should have been controlled by doing specific analysis (contacted before surgery/not contacted) in order to assess its impact on the third measurement. Furthermore, as this service was offered by two social workers, we would have had to ensure the consistency of the psychosocial intervention. Thus, this represents a limitation to this study.

The general population's level of anxiety assessed by the State-Trait Anxiety Inventory (STAI) - Spielberger (1983) is established with categories for age and gender. For women between 50 and 54 years old, the average anxiety level is 32.60 (S.D. 7.30). One standard deviation higher than average indicates a high anxiety level (39.90). This means that some of the women who participated in this study (with an average age of 52) had a high level of anxiety before the educational intervention since their level of anxiety was greater than

Table One: Pre-operative anxiety levels at the three measurement points

Anxiety	E Group (n = 30) Individualized intervention		C Group (n = 30) Standard intervention	
	Average	St. deviation	Average	St. deviation
Anxiety before the educational intervention: IAS #1	52.00	15.32	46.33	12.58
Anxiety immediately after the educational intervention: IAS #2	41.47	12.18	40.63	11.98
Anxiety the day before surgery: IAS #3	47.03	14.45	44.90	11.76

Table Two: Effectiveness of the educational intervention on anxiety reduction immediately after the educational intervention and the day before surgery

Effectiveness	E Group (n = 30) Individualized intervention		C Group (n = 30) Standard intervention		Difference between the two groups	
	Reduction in anxiety	p value	Reduction in anxiety	p value	Reduction in anxiety	p value
Effect immediately after the educational intervention: IAS #1 - IAS #2	10.53	<0.01	5.70	<0.01	4.83	0.05
Effect the day before surgery: IAS #1 - IAS #3	4.84	0.03	1.43	0.51	3.41	0.27

39.90, the standard deviation being higher than the normative average with averages of 46.33 (S.D. 12.58) and 52.00 (S.D. 15.32) in the control and experimental groups, respectively. Thus, the perception of threats linked to breast cancer and surgery appears to be real.

The individualized psychocognitive educational intervention was intended to reduce the level of anxiety by directly influencing the perception of threat and by satisfying the need for information related to the distressing event. The study results show that immediately after the educational intervention, it was observed that the two types of educational interventions, experimental and control, significantly reduced the anxiety level.

While few studies have assessed the impact of an individual educational intervention done by a nurse with clients awaiting surgery, the results of this study appear to be related to those of Shimko's study (1981) with 81 clients awaiting neurosurgery where it was observed that the anxiety level dropped by an average score of 6.0 immediately after an individual or small-group educational intervention focusing on cognitive and psychomotor aspects. The results suggest that giving only information is enough to reduce the anxiety level immediately after the educational intervention.

The study by Richardson and O'Sullivan (1991) using a quasi-experimental design with 60 clients awaiting elective surgery showed that the group that received an individual educational intervention on the day prior to surgery had an anxiety level significantly lower ($F [1.58]=4.97$; $p<0.05$) ($M 40.43$; $S.D. 9.76$) than the group that did not receive any such intervention ($M 47.16$; $S.D. 14.97$). The educational intervention provided support to the client. The content focused on fears or apprehensions and issues related to the surgery.

Clinically, with the IAS, a reduction of 5.7 in the anxiety level means that two statements out of 20 (i.e. 10% of the statements) have been reduced by two and that another one has dropped by one, or that five statements (i.e. 25% of the statements) have been reduced by one, which could be considered significant. A reduction of 10.53 in the level of anxiety represents five statements out of 20 (i.e. 25 % of the statements) that have incurred a drop of two on the Likert scale or 10 statements (i.e. 50% of the statements) that have dropped by one, for instance, which represents an additional significant reduction. An added reduction of the anxiety level equal to 4.83 is therefore significant for women awaiting mastectomies.

In the control group, the educational intervention started with the pre-admission health record (checking on completion of diagnostic tests and pre-operative consultations and usual data collection). Fears or concerns regarding the surgery, hospital stay, or return home were examined, but we did not explore the fears, real or anticipated, resulting from the cancer diagnosis and mastectomy announcement, nor the relationship with the spouse and family since the diagnosis. The coping strategies used by the women to problem-solve, and their existing support network represented other elements that were explored with the women but that did not play a leading role. However, the teaching material used and the informational content aimed at preparing women for surgery and self-care were the same for both types of educational intervention and these similarities probably contributed to reducing pre-operative anxiety. This could also explain why the difference between these two educational interventions is not larger than 4.83.

It is possible that the length of the educational intervention administered to the experimental group, which is significantly greater than that of the control group ($p<0.01$), also contributed in a noticeable way to the reduction of the anxiety level in this group. The greater length of time devoted to active listening and expression of emotions may potentially contribute to further reducing anxiety by helping women communicate all of their concerns and questions related to the surgery and breast cancer diagnosis and to receive needed answers.

With a high level of anxiety, which is the case for the women in this study, Lazarus and Folkman (1984) state that the individual will use emotion-focused strategies before using problem-focused

strategies. The fact that the experimental educational intervention was focused on the expression of feelings and emotions and on support may have resulted in a more pronounced impact on anxiety reduction as the approach used was more closely related to an emotion-focused coping strategy. We are inclined to believe that this sizeable reduction of anxiety in the experimental group was in a large part due to the very nature of the experimental intervention.

The context of the experimental educational intervention, for instance the fact that the meetings took place in a different room (friendly and intimate) than that used by the control group, may have also fostered better feelings in the women and helped lower their anxiety levels.

In the experimental group, some of the effects of the educational intervention on anxiety reduction seem to last until the day before surgery (4.84 reduction; $p=0.03$). However, the difference between the effect of both types of educational interventions on the day before surgery is not significant ($p=0.27$). Thus, one cannot claim an increased effectiveness of the experimental intervention.

In the experimental group, the effectiveness of the educational intervention appears to be associated with attending with a companion ($r^2=0.43$; $p=0.02$). The individualized psychocognitive approach allowed the women to be accompanied. During the educational intervention, the significant other's (friend, spouse, or family member) participation and support were sought and encouraged. This may have contributed to a further decrease in the anxiety level. Moreover, women were invited to attend the education intervention with a companion in both the experimental and control groups. However, in the control group's educational intervention, there was no systematic strategy for inviting participation and support from the women's companions.

Conclusion

The nurse is in a privileged position to help and support women awaiting mastectomies. It would appear that an educational intervention during the pre-operative period can help reduce anxiety in these women. A psychocognitive-based educational intervention also appears to help further reduce their anxiety.

The results of this study confirm the importance of planning and development of educational interventions for this population. This study especially demonstrated the importance of focusing educational interventions not only on surgery-related cognitive aspects but also on the psychological aspects (expression of fears, threats, apprehensions) linked both to the surgery and in particular to the cancer diagnosis. It is increasingly vital that efforts be sustained and encouraged to improve the quality of the education provided to women awaiting mastectomies in spite of environments that can sometimes not be conducive to the humanization and individualization of nursing interventions. It may also be useful to consider some form of follow-up for these women between the time of the educational intervention and the day before surgery in order to maintain an acceptable anxiety level for optimal quality of life during this difficult episode of their breast cancer treatment. Such follow-up, via telephone or in any other form, could be the topic of further research and could help determine if clinical practices need to be changed so that women can benefit from an educational intervention aimed at reducing their anxiety until the day before surgery.

Additional studies could also help identify the specificity of the educational approaches used in pre-operative education in order to better assess the contribution of the various elements of the assessed intervention. It would also be necessary to better control the role of some confounding variables such as referrals to other psychosocial resources, especially when one wants to measure the duration of the reduction in anxiety levels until the day before surgery. Moreover, one should ensure that the physical environment for the educational intervention be identical for the groups under comparison.

References are found on page 176.

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Advancing the quality of oncology nursing care: Interlink Community Cancer Nurses' model for reflective practice

By Doris Howell and Beth Pelton

Abstract

Since 1996, Interlink Community Cancer Nurses have been using reflective practice as a team to share knowledge and experience amongst peers. The use of reflective practice enables the nurse to examine decision-making in patient situations and uncover the knowledge and artistry that is embedded in nursing practice. This article describes how reflection is practised by specialist cancer nurses to advance the quality of caregiving. The use of a structured framework for reflection which incorporates ways of knowing in nursing is an essential feature of the Interlink model for reflection. The development of a process for reflection within the Interlink program has at times been challenging. However, the Interlink nurses' experience with reflection is believed to be critical to the ongoing development of the program and the individual nurse. Interlink nurses have found that guided reflection, the creation of an environmental milieu for reflection and personal knowing, and self-evaluation are critical to the process of becoming a self-reflective practitioner.

Reflective practice has been described as a method for understanding the artistry of nursing practice and for realizing therapeutic potential (Antrobus, 1997), and as a means of uniting the gap between theory, practice, and evidence-based decision-making in nursing (Johns, 1996). Interlink Community Cancer Nurses have been utilizing self-reflection to explore the cancer patients' experience with illness, to uncover knowledge to guide decision-making and practice, and to illuminate nursing interventions used in the therapeutic process. The process of reflection provides the Interlink nurse with an opportunity to uncover the reasons for adopting ways of caring for patients, and for exploring new avenues for supporting patients through the experience of cancer.

Interlink Community Cancer Nurses is a nonprofit, community nursing agency which is modeled after the Macmillan nurse program in the United Kingdom (Bunn, 1988). Interlink nurses function as independent consultants providing expert oncology nursing support to patients and families across the continuum of

cancer from early diagnosis through to cure/remission or palliation and bereavement care. Interlink nurses contribute to the clinical management of disease symptoms and treatment side-effects while providing essential psychosocial support. Interlink nurses empower adults and children with cancer and their families to access the care and support required at all stages of illness. The goals are to lessen the burden of living with cancer, promote optimal functioning and well-being, and improve or maintain quality of life. Interlink nurses also act as a specialized education and resource to health care professionals working collaboratively with them in meeting cancer patients' needs.

The independent nature of the Interlink nurse's practice and the provision of consultative support to other care providers in the community demands that Interlink nurses continually advance their expertise in order to realize positive patient outcomes, and to demonstrate their contribution in the care of persons with cancer and their families. Interlink nurses use reflection to increase their understanding of the empirical and humanistic foundation of caregiving and as a means for advancing the quality of their nursing care.

Reflecting on care can provide nurses with insight into their practice and an opportunity for learning. Using a reflective process to explore nursing practice with people with cancer can provide a rich detailing of their experience and the therapeutic role of the nurse. Interlink nurses have noted that the reflective process stimulates their personal growth and development, deepens their individual practices, enhances relationships with patients, and improves problem-solving. The use of reflection in practice has been thought to contribute to the enhancement of deep learning (Lowe & Kerr, 1998), and to facilitate effective problem-solving through a self-evaluation process (Kolb, 1975).

Reflective practice also assists Interlink nurses in identifying gaps in their knowledge and topics for future learning. For instance, in reflecting upon an adolescent's response to cancer, Interlink nurses identified the need to learn more about the stages of human growth and development, as well as adolescent grieving and coping. Reflective practice has been identified as a method for nurses to assess their personal level of competence in order to maintain licensure as a registered nurse in Ontario (Wansbrough, 1996). Schon (1983) and Powell (1989) believe the ability to reflect is essential for nursing competence, creates effective practitioners, and sustains practitioner development.

A conceptual model for reflection

The use of a conceptual model to guide reflection, the development of personal knowing or self-reflection, and the creation of an environment for reflection have been identified as the critical success factors in implementing reflective practice within the Interlink program.

Johns (1995) identified the need for reflection to start with a model to provide guidance and structure and to facilitate the development of the skills of reflection. Implementing a structured model for reflection assists Interlink nurses in critically analyzing a patient situation rather than merely retelling the patient's story and the events surrounding the nurse's interaction with the patient. A structured model for reflection allows the practitioner the opportunity to understand deeper meanings in situations, uncover the theoretical and scientific knowledge utilized, and explore with peers new knowledge or experience that might have been helpful in caring for the patient. Johns' (1995) model for structured reflection, which incorporates Carper's (1978)

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fundamental ways of knowing in nursing, was adapted as the framework to guide the process of reflection within the Interlink program (see Table One).

The framework is particularly useful because it provides the nurse with an opportunity to explore not only the scientific or evidence base incorporated within nursing care but also the art of caregiving. Carper's four patterns of knowing have been described as providing a pathway through which the fullness of the nursing situation can be known (Boykin & Schoenhofer, 1991). Critical patient situations are described and explored utilizing the four parameters of knowing in nursing: empirics, moral (ethical) knowing, personal knowing, and aesthetics (Carper, 1978). The framework provides a structure for reflecting on care and guides the nurse in uncovering the knowledge embedded within his/her practice and additional knowledge that might have been incorporated to advance therapeutic nursing care. The model promotes the nurse's ability to reflect on his/her own practice behaviour through an exploration of which aspect of knowing has influenced caregiving and has contributed to the adoption of particular nursing interventions and decision-making.

Expanding the framework for reflection

Interlink nurses are frequently involved in patient situations that require negotiation and advocacy for resources to meet the needs of the cancer patient and the family. The need to be aware of the social and political environment in which care is provided is becoming an important element of the Interlink nurse's role. Interlink nurses are thus exploring the ways in which they can use the principles of community health promotion and advocacy in their practice. Through the reflective process, Interlink nurses uncover system issues that require system change and political action. For example, an Interlink nurse wrote a letter to the chair of a local cancer hospital's community advisory committee seeking a voice for those receiving care within a restructured cancer care system. In addition, an Interlink nurse and a student met with women at a housing complex to provide education on breast health to this group who seldom use formalized breast screening programs. Subsequently, a fifth pattern of knowing, namely sociopolitical knowing (White, 1995), has been added to the framework for reflection.

Table One: Model for structured reflection (10th version)

Carper's ways of knowing	Questions for reflection
Aesthetics	Art of nursing care What was I trying to achieve? What feelings were described to me by the patient? Why did I respond as I did? What were the consequences?
Personal	How did I feel in this situation? What internal factors, belief systems or values were influencing me?
Ethics	How did my actions match with my beliefs? What ethical principles were involved?
Empirics	What knowledge should have informed me? What theory might have helped describe the situation? What evidence exists for the interventions utilized?

Reprinted with permission from Johns (1995).

Sociopolitical knowing has been envisioned as useful for both activism for change within a community (Hagedorn, 1995), and for understanding power relations that may influence health within a community (Sheilds & Lindsey, 1998). Interlink nurses are learning through reflection to be conscious of the ways in which change can be influenced in order to mobilize a community of support around the person with cancer and the family. Interlink nurses reflect on the need to be politically active in the context of their own personal resources, energy, and belief systems.

As the Interlink nurses explore patient situations, they frequently uncover the art of care or an intuitive element (Benner, 1984) which has guided nursing practice. The aesthetic way of knowing has been described by Johns (1995) as the core way of knowing in practice, informed by the empirical, the personal, and the ethical dimensions of practice. It has been recognized that individual patient and family responses to a cancer diagnosis cannot always be described from a theoretical or scientific perspective. Patient responses and reactions to living with cancer are frequently complex and are related to the meaning that an individual attaches to his/her life and experience of living with cancer (Howell, 1998). These situations can be understood only by listening to and actually hearing the patient's story. The nurse-person process is not data-based; it is human-based. This kind of dialogue is unscripted and through this relationship nurses demonstrate a commitment to be with patients to listen, respect, provide, and be involved as directed by patients (Mitchell, 1999).

A sixth way of knowing was added to the conceptual model used to guide reflective practice, namely that of unknowing. Unknowing has been described as an awareness that the nurse does not and cannot know fully the client's perspective (Munhall, 1993). Adopting the element of unknowing into the model was important for Interlink nurses to describe the humanistic element of their

Table Two: Interlink Community Cancer Nurses' framework for reflection

Ways of knowing	Questions for reflection
Aesthetics	Art of nursing care What was I trying to achieve? What feelings were described to me by the patient? Why did I respond as I did? What were the consequences?
Personal	How did I feel in this situation? What internal factors, belief systems or values were influencing me?
Ethics	How did my actions match with my beliefs? What ethical principles were involved?
Empirics	What knowledge should have informed me? What theory might have helped describe the situation? What evidence exists for the interventions utilized?
Sociopolitical (White, 1995)	Where and how can my voice be heard? What change action is needed to respond to these patient needs?
Unknowing (Munhall, 1993)	What is unable to be explained in the patient situation and is just the person's way of being in the world?

Adapted with permission from Johns (1995).

practice as a particular way of caring that goes beyond the medical domain and to ensure that patient situations are not merely reduced to an analysis of the empirical. Interlink nurses recognize that there is an element of unknowing in providing humanistic care. This element requires that the nurse listens to herself and is open to learning about the interaction between patient and self in order to enhance care and support. Professional practice demands a comfort with the unknown in light of a broad knowledge base and understanding of the lived experience of the person with cancer. The model for reflection adopted by Interlink Community Cancer Nurses which incorporates the six ways of knowing and the questions that are used to guide reflection are described in Table Two.

Using the framework for reflection

In using the framework for reflection, the Interlink nurse chooses a patient who has been cared for in her practice and reflects upon care provided. Nurses may choose to focus on only one or all of the elements within the reflective framework, as some nurse-patient situations demand attention to particular elements. Nurses who are just embarking on a self-reflective process will find the use of all of the elements in the framework more helpful.

The reflective process for the Interlink nurse involves presentation of a case situation to the Interlink nursing team followed by a reflection on the care provided using the framework. The nurse prepares the presentation prior to the team review and, consequently, may have already reviewed the literature for additional information that might have informed her practice. Reflecting on the empirical way of knowing in nursing may lead the Interlink nurse to further explore what is known about a particular concept or theoretical construct which could be used to advance her practice. For example, one of the Interlink nurses reviewed the literature on coping to empirically inform her practice with a woman experiencing significant distress as a result of her breast cancer diagnosis. Following the nurse's reflective presentation, the team and a facilitator (Practice Development Leader) discuss the nurse's presentation and provide feedback on the nurse's practice giving guidance on additional knowledge or practical advice that may have informed her practice and may be helpful in future patient and nurse interactions. The following is an excerpt from one of the reflective practice presentations.

Reflecting on a patient situation

The nurse tells the story of Sally, a woman in her late 70s who is fiercely and proudly independent. For months, Sally had complained to her family physician about constipation and general abdominal fullness. Eventually she ended up in the emergency department with vaginal bleeding and abdominal obstruction. Immediate surgery revealed a diagnosis of Stage III, ovarian cancer. She spent several weeks in hospital, most of them in the intensive care unit. She was seriously ill and almost died. She has little clear memory of that time except she remembers hearing the surgeon tell her that he had, "got it all." Sally was anxious to return home, but became worried and frustrated when she did not regain her former health and energy within a week of discharge. Within a month she was having nightmares of her time in hospital. However, she did not want further assistance from a psychiatrist. At this time she did not believe that she was disease-free and she felt the doctors were not telling her everything and were minimizing her concerns. Her focus was on regaining her strength and the use of her scooter, which was the symbol of her independence. The assistance of a community mental health occupational therapist was sought. This did not help. During this time, she continued to believe that she still had cancer because she continued to be constipated (x-rays and scans were negative).

The nurse reflects

Aesthetics. I had many wants for Sally. I wanted her frightening dreams and memories resolved. I wanted her to feel less impatient and frightened by her fatigue, to feel confident in the use of her scooter, and to be able to independently leave her apartment. I wanted her to get back to socializing. These were the things that Sally told me she wanted. I heard the anguish of her most telling statement, "I never thought getting sick and dying would happen to me...." I felt connected with her and wanted to reduce her anguish. I wanted Sally to know that I believed her and wanted to help her. I believed that my feelings of connection with Sally, and my intention to help her, rendered me open to her. I need to, intend to, be still, to listen, to empty my thoughts of my agenda. Johns (1995) tells us that the aesthetic way of knowing is the core way of knowing in practice informed by the empirical, the personal, and the ethical dimensions of practice. My aesthetic way of knowing in working with Sally was my comprehension of her anguish in realizing and admitting her vulnerability and her mortality.

Personal. Instead of really listening, and being with Sally in her anguish, I got busy doing "fix it" things. I left Sally alone in her anguish, which increased as my "fix-it" actions did not help. The goal or "outcome" I envisioned - that of as much independence as possible - was also Sally's goal. If, however, I had grasped what I knew - that Sally did not want this anguish and that she was used to taking care of herself - I would have engaged with Sally as another person with many of the same questions and worries about vulnerability and mortality. We each would have learned about self and the other (Parse, 1998). Sally might - or might not - be riding her scooter these days. It doesn't seem to matter what she is doing. She is doing and being with less anguish, more confidence and hope (despite the "fix-it" nurse). And she continues to enable me to learn and discover in relationship with her.

Ethics. Also with reflection, I realize it is the questions about ethical knowing that have helped me to realize I could have been there with Sally in terms of respecting Sally as the expert in her own life and in terms of sharing myself with Sally as a person, and as a person without all the answers. My actions did not match my beliefs. I became more focused on "fixing things" for Sally according to my perspective. It took me a long time to hear Sally's perspective; the scooter was not her issue. The facts that she had been very ill, had almost died, and that she still did not have full control of her living - these are her issues. An ethical approach to care allows the nurse to be fully present with people and to hear their perspective and ways of managing the illness that confronts them.

Empirics. I need to enable myself to be guided by a theoretical perspective more consistent with a humanistic way of caring for Sally. I reviewed the literature regarding humanistic nursing responses to complex patient reactions, including Parse's Human - Becoming Theory (Parse, 1998). I have learned from Sally that I can heed the pushes and pulls - the ambiguities and contradictions - in conversations. Coping theory also helped me to understand Sally's early traumatic reactions to the diagnosis such as the nightmares and the turmoil they created for her.

Sociopolitical knowing. In this practice situation, reflection did not include sociopolitical knowing. However, in other situations the nurse might reflect upon the system change or advocacy that may be necessary to support persons living with cancer in the community. As an advocate, the nurse might help others to hear and understand the patient's perspective.

Unknowing. I realized that I do not fully know the other person's experience of living with cancer and recognize the need to be open to the other and hear that person's story and perspective. To really listen. I wanted Sally to know that her physicians and I were paying attention to her so that she would believe she was well and would be able to focus on living. While setting goals with Sally to be well, I experienced inner turmoil knowing that her cancer will likely recur. I

wanted to help her get on with her living. In helping her to find her way to living, and to understand her perspective, I asked a number of assessment questions such as: "What do you hope will happen for you? What help do you need for that to happen?" These questions caused great anxiety in Sally. She would ask for help or direction, then reject ideas. She would express her feelings and frustrations, but would respond to any problem-solving suggestions with, "I don't want to talk about it." I was feeling frustrated with Sally's push-pull presentations. I began to listen more and ask fewer questions. However, I was not articulating - or even consciously acknowledging - this frustration. I lost focus. I wanted to be there for Sally on *her* terms, and according to *her* perspective and feel that I am open to this way of practice. I believe that I practise in this way. However, unknowingly, I was listening to my own agenda and developed a stance of wanting to fix things in this situation.

The nurse's ability to reflect on her practise in this situation provides insight into the ways in which she was practising and provides an opportunity to explore more effective ways of practising and caring for others.

Becoming a self-reflective practitioner

Personal knowing and self-reflection by the nurse has been one of the most challenging elements to incorporate within reflective practice sessions which are presented to all members of the Interlink nursing team. Yet, personal knowing and self-reflection can be one of the most positive ways of enhancing relationships with colleagues and patients. Personal knowing concerns the inner experience of becoming a whole, aware self and it is through knowing the self that one is able to know another human being (Chinn & Kramer, 1995).

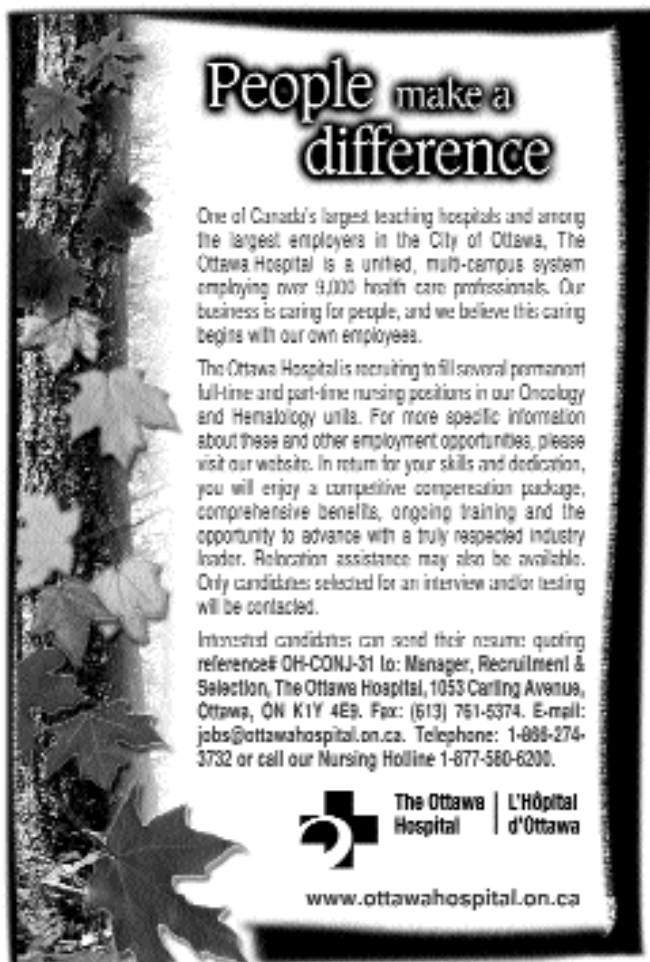
Self-reflection is a powerful tool to increase self-understanding and reveal reasons for the nurse's behaviour and potential barriers to

the therapeutic relationship. The outcomes of nursing action are clearly dependent on the sort of person the practitioner is and the nurse must be aware of who he/she is so that personal concerns do not interfere with the patient's exploration of his/her concerns (Johns, 1995). Yet, to embark on a process of self-reflection, to reveal personal knowing in a patient situation can be intimidating for the nurse.

Reflective practice provides nurses with the opportunity to articulate the underlying behavioural strategies that accompany interactions and inform them about their own individual patterns of interpersonal behaviour. Perception of personal feelings in order to understand and accept the patient or relative without prejudice, particularly in an environment of cultural diversity, is critically important. However, it must be recognized that the process of self-reflection creates a sense of vulnerability within the nurse as professional role barriers are let go and the ways in which the nurse practices are revealed to both self and colleagues. It is only through a process of self-reflection that differences between professional barriers and personal boundaries can be worked through in each nurse-patient relationship.

Shaping a reflective practice environment

Promoting and shaping a reflective environment enables learning to occur from the lived experiences of nurses. Interlink nurses are poised to engage more deeply in self-reflection and peer reviewed reflection. The use of reflective practice in monthly nursing team meetings has been a slow process for Interlink nurses as trust and the development of relationships between team members evolved. An experienced facilitator who is not a practising Interlink nurse has been critical in guiding the process. The facilitator provides feedback and guidance to the individual



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nurse using the reflective framework, as well as to team members to encourage them to provide honest, constructive feedback to their colleague. During the first few months, colleagues tended to provide only positive feedback, but now they feel more comfortable to discuss other interventions that may have been helpful. Gradually, the milieu was created within the Interlink nursing team and they have evolved from timidly reflecting on their practice with each other to being able to make suggestions for alternate interventions. Interlink nurses experienced varying degrees of discomfort and excitement. An environment of trust has been critically important in order to be able to move from merely supporting interventions of colleagues to truly reflecting on practice decisions and actions and to exploring potentially new ways of practising.

Reflective practice demands that long-held beliefs about professional roles and attitudes must be questioned. Professional role barriers may complicate our ability to create a humanistic, personal connection with patients. The nurse-patient relationship is another person-to-person relationship, but it is more complex and requires an awareness by the nurse of personal boundaries in order to practise therapeutically. For example, we are very much present with the grieving patient, may even cry with him/her, but we are not available to him/her during off-duty time. Feeling emotional connections with patients, which is not the same as emotional involvement, leaves the nurse vulnerable to experiencing grief when cancer recurs or when the patient dies. Admitting to these emotional connections with patients to colleagues during a reflective practice session may leave many nurses feeling open to criticism as an ineffective nurse.

Reflective practice must not be perceived as a way of identifying deficiencies in practice, but as advancing our understanding of the art and knowledge embedded in the care of patients and their families and the ways in which care might be enhanced. Nurse leaders and colleagues must help to create an atmosphere of mutual respect that promotes a feeling of trust and safety in order to lessen the feeling of vulnerability inherent in revealing one's ways of working with patients.

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The power of reflection

One of the most challenging aspects of developing structured reflection is preventing self-reflection from becoming purely an academic exercise. Reflective practice has the potential to uncover and articulate the essential knowledge embedded in nursing practice and to assist in articulating the art of care. Self-realization has been described as both exciting and awesome. Fay (1987) describes the process of reflection as one of enlightenment, empowerment, and emancipation. Enlightenment is to understand oneself in the context of defining and understanding practice; empowerment is having the courage and the commitment to take the necessary action to change oneself; and emancipation is to liberate oneself from previous ways of being, to become who you need to be in order to achieve desirable practice. Interlink nurses are feeling enlightened through the practice of self-reflection and are striving to achieve empowerment and emancipation.

Conclusion

The nurse of the future is described as a knowledge worker, able to articulate the knowledge that guides decision-making. Interlink nurses find that a conceptual framework helps to guide them on the path to adopting reflective practice. At times it has been challenging to explore patient situations more deeply. However, the process has been an important one for the development of the quality of the Interlink nurse's practice and has contributed to individual development, and growth within the team. Nurses may need time to develop the skills of reflection, and considerable practice in order to internalize reflective cues as a way of viewing practice. Nurses without guidance and mentorship may experience difficulty in accessing contemplative thinking and in their ability to think through the situation deeply, considering reasons for thoughts, feelings, and actions. Reflective practice is fostered through environments that provide mentorship and guidance to the nurse as he or she journeys along the path to becoming a self-reflective practitioner. Interlink nurses are committed to using reflection in order to continually advance the quality of caregiving and to articulate their role in positively influencing the cancer person's experience of living with cancer.

Améliorer la qualité des soins infirmiers en oncologie: modèle de réflexion sur la pratique proposé par les infirmières en oncologie d'Interlink œuvrant en santé communautaire

Par Doris Howell et Beth Pelton

Abrégé

C'est depuis 1996 que les infirmières en oncologie d'Interlink œuvrant en santé communautaire utilisent, en équipe, la réflexion sur la pratique afin de partager connaissances et expériences entre pairs. La méthode de la réflexion sur la pratique permet à l'infirmière d'examiner la prise de décisions concernant des cas réels et de découvrir les connaissances et l'art qui sous-tendent la pratique infirmière. Cet article décrit l'usage de la réflexion que font des infirmières spécialisées en cancérologie afin d'améliorer la qualité des soins qu'elles prodiguent. L'utilisation d'un cadre structuré pour la réflexion incorporant divers modes d'acquisition du savoir constitue une caractéristique essentielle du modèle Interlink pour la réflexion. L'élaboration d'une démarche visant à guider la réflexion au sein du programme Interlink n'a pas toujours été facile. Toutefois, on estime que l'expérience des infirmières Interlink en matière de réflexion a joué un rôle critique dans le développement continu du programme et dans l'épanouissement des infirmières individuelles. Les infirmières Interlink ont remarqué que la réflexion dirigée ainsi que la création d'un milieu favorable à la réflexion, à la connaissance de soi et à l'autoévaluation sont des éléments fondamentaux du cheminement de l'infirmière privilégiant la réflexion sur la pratique.

La réflexion sur la pratique a été décrite comme une méthode permettant de comprendre l'art de la pratique infirmière et de réaliser le plein potentiel thérapeutique (Antrobus, 1997), et de combler le fossé, dans les soins infirmiers, entre la théorie, la pratique et la prise de décision fondée sur des données probantes (Johns, 1996). Les infirmières en oncologie d'Interlink œuvrant en santé communautaire ont utilisé l'auto-réflexion afin d'explorer le vécu de la maladie chez leurs patients atteints de cancer, pour dégager les connaissances qui orientent la prise de décision et la pratique et pour éclairer les interventions infirmières utilisées tout au long du processus thérapeutique. La démarche de réflexion aide l'infirmière Interlink à dégager les raisons pour lesquelles on adopte telles ou telles manières de soigner les patients et à explorer de nouvelles avenues pour ce qui est du soutien offert aux patients tout au long de l'expérience du cancer.

Les infirmières en oncologie d'Interlink forment un organisme de soins infirmiers communautaires à but non lucratif constitué sur le modèle du programme des infirmières Macmillan au Royaume-Uni

(Bunn, 1988). Les infirmières Interlink œuvrent à titre de consultantes indépendantes qui prodiguent des soins infirmiers en oncologie spécialisés à des patients et à leurs proches tout au long du continuum du cancer, depuis le diagnostic précoce jusqu'à la guérison ou la rémission ou jusqu'à la palliation et le soutien aux endeuillés. Les infirmières Interlink participent à la gestion clinique des symptômes de la maladie et des effets secondaires des traitements tout en fournissant un soutien psychosocial essentiel. Elles habilitent les adultes et les enfants atteints de cancer et leurs proches à accéder aux soins et au soutien dont ils ont besoin à chacune des phases de la maladie. Elles se donnent pour buts d'alléger le fardeau que représente le vécu du cancer, de promouvoir un fonctionnement et un bien-être optimaux et d'améliorer la qualité de vie – ou pour le moins de la maintenir à son niveau existant. Les infirmières Interlink se font également personnes-ressources spécialisées auprès des professionnels de la santé qui œuvrent à leurs côtés pour répondre aux besoins des personnes aux prises avec le cancer.

La nature autonome de la pratique de l'infirmière Interlink et la prestation de consultations de soutien relatives aux autres professionnels de la santé communautaire exigent des infirmières Interlink qu'elles fassent constamment progresser leur expertise si elles veulent obtenir des résultats positifs pour leurs patients et montrer la valeur de leur contribution aux soins des personnes atteintes de cancer et de leurs proches. Les infirmières Interlink font appel à la réflexion pour approfondir leur compréhension des assises empiriques et humanistes de la prestation des soins et pour améliorer la qualité des soins qu'elles dispensent.

La réflexion sur les soins prodigués peut permettre aux infirmières d'acquérir une connaissance approfondie de leur pratique et peut constituer une occasion d'apprentissage. L'utilisation d'une démarche fondée sur la réflexion en vue d'explorer les soins infirmiers prodigués aux personnes atteintes de cancer peut fournir de riches détails sur leur vécu de la maladie et sur le rôle thérapeutique de l'infirmière. Les infirmières Interlink ont rapporté que la démarche de réflexion stimule leur épanouissement et leur développement personnels, donne un sens plus profond à leur pratique individuelle, rehausse les relations avec les patients et améliore la résolution de problèmes. On estime que l'utilisation de la réflexion dans la pratique contribue à améliorer l'assimilation de connaissances profondes (Lowe et Kerr, 1998) et à accroître l'efficacité de la résolution de problèmes par le biais d'une démarche d'autoévaluation (Kolb, 1975).

La réflexion sur la pratique aide également les infirmières Interlink à déterminer les lacunes au niveau de leurs connaissances et les sujets qu'elles pourraient couvrir dans leur apprentissage futur. Par exemple, en se penchant sur la réaction d'un adolescent face au cancer, les infirmières Interlink ont décidé qu'elles devaient étudier en profondeur les étapes de la croissance et du développement humains ainsi que les domaines de l'adaptation et du deuil chez les adolescents. La réflexion sur la pratique constitue une méthode en vertu de laquelle les infirmières peuvent évaluer leur propre niveau de compétence en vue de conserver leur immatriculation en Ontario (Wansbrough, 1996). Schon (1983) et Powell (1989) pensent que l'aptitude à la réflexion est une composante essentielle de la compétence en soins infirmiers, qu'elle engendre des praticiennes d'une grande efficacité et qu'elle appuie le perfectionnement de ces dernières.

Modèle conceptuel pour la réflexion

Au sein du programme Interlink, on a dégagé les facteurs critiques de succès suivants pour la mise en œuvre de la réflexion sur la pratique: utilisation d'un modèle conceptuel pour orienter la réflexion, développement de la connaissance de soi ou de l'auto-

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réflexion, création d'un environnement propice à la réflexion.

Johns (1995) a indiqué qu'il fallait commencer par un modèle qui fournirait l'orientation et la structure nécessaires et faciliterait le développement des compétences relatives à la réflexion. La mise en œuvre d'un modèle structuré pour la réflexion aide les infirmières Interlink à effectuer l'analyse critique d'un cas plutôt que de se contenter de rapporter l'histoire du patient et des événements entourant l'interaction de l'infirmière avec ce dernier. Un modèle structuré pour la réflexion permet à la praticienne de saisir dans les situations des significations plus profondes, de révéler les connaissances théoriques et scientifiques utilisées et d'explorer avec ses pairs de nouvelles connaissances ou expériences qui auraient pu être utiles sur le plan des soins au patient. Le modèle de réflexion structurée proposé par Johns (1995), qui incorpore les modes d'acquisition des connaissances de Carper (1978), a été adapté comme cadre d'orientation de la démarche de réflexion au sein du programme Interlink (voir le tableau un).

Ce cadre est extrêmement utile parce qu'il donne à l'infirmière la possibilité d'explorer non seulement la base scientifique ou les données probantes intégrées aux soins infirmiers mais aussi l'art de la prestation de soins. Il a été dit des quatre schémas d'acquisition du savoir définis par Carper qu'ils constituent la voie grâce à laquelle on peut saisir la totalité de la situation de soins infirmiers (Boykin et Schoenhofer, 1991). Des cas critiques sont décrits et explorés à la lumière des quatre paramètres de l'acquisition du savoir infirmier: dimension empirique, dimension morale (éthique), dimension personnelle et dimension esthétique (Carper, 1978). Le cadre fournit une structure propice à la réflexion sur les soins; il guide l'infirmière dans sa découverte des connaissances qui sous-tendent sa pratique et les connaissances additionnelles qui ont pu y être incorporées afin de rehausser les soins infirmiers thérapeutiques. Le modèle favorise la capacité de l'infirmière à réfléchir sur son propre comportement de pratique en explorant celui des paramètres de l'acquisition des connaissances qui a influé sur l'épisode de soin et a entraîné l'adoption d'interventions infirmières et d'une prise de décisions particulières.

Élargissement du cadre de réflexion

Les infirmières Interlink font souvent face à des situations de soins qui les amènent à négocier et à défendre les intérêts des patients en vue d'obtenir les ressources permettant de répondre aux besoins des patients atteints de cancer et de leurs proches. Ainsi, la prise de conscience de l'environnement social et politique de la prestation des soins devient un élément important du rôle des infirmières Interlink. Ceci les amène à explorer les manières dont elles peuvent utiliser, dans leur pratique, les principes de la promotion de la santé communautaire et de la défense des intérêts des patients. Grâce à la démarche de réflexion, les infirmières Interlink dégagent les enjeux relatifs au système de soins qui exigent des changements au niveau du système ainsi que des actions politiques. Par exemple, une infirmière Interlink a écrit une lettre au président du comité consultatif communautaire d'un centre anticancéreux en vue d'y donner une voix aux personnes recevant des soins dans un système restructuré des soins aux personnes atteintes du cancer. Dans un autre cas, une infirmière Interlink et une étudiante infirmière ont rencontré les femmes d'un ensemble immobilier afin de les informer en matière de santé du sein, elles qui utilisent rarement les programmes structurés de dépistage du cancer du sein. Par conséquent, on a ajouté au cadre de réflexion un cinquième mode d'acquisition des connaissances, le savoir sociopolitique (White, 1995).

Le savoir sociopolitique a été jugé utile à la fois pour l'activisme en faveur du changement dans la collectivité (Hagedorn, 1995) et pour la compréhension des rapports de force qui peuvent influencer sur la santé au sein d'une collectivité (Sheilds et Lindsey, 1998). Les infirmières Interlink apprennent, par le biais de la réflexion, à se sensibiliser aux diverses manières d'influencer le changement afin de mobiliser un réseau de soutien autour de la personne atteinte de cancer et de ses proches. Les infirmières Interlink examinent le besoin qu'elles ont de

militer au niveau politique à la lumière de leurs ressources personnelles, de leur énergie et de leur propre système de croyance.

Lorsque les infirmières Interlink explorent les situations de soins, elles mettent fréquemment au jour l'art de dispenser des soins ou un élément de nature intuitive (Benner, 1984) qui orientait la pratique infirmière. Selon Johns (1995), le mode esthétique d'acquisition des connaissances est au centre du savoir relié à la pratique, et il est éclairé par les dimensions empirique, personnelle et éthique de la pratique. Il a été établi que les réponses d'un patient individuel et de ses proches à un diagnostic de cancer ne peuvent pas toujours être décrites selon une perspective théorique ou scientifique. Les réponses et les réactions des patients au vécu du cancer sont souvent complexes et se rapportent à la signification que la personne attribue à son vécu et à son expérience du cancer (Howell, 1998). Ces situations ne peuvent être comprises qu'en écoutant l'histoire du patient et en en saisissant la portée réelle. La relation entre l'infirmière et la personne ne repose pas sur des données; elle est de nature humaine. Ce genre de dialogue ne suit pas un scénario préétabli et dans le cadre de cette relation, les infirmières montrent qu'elles s'engagent à être aux côtés des patients pour l'écoute, le respect, le pourvoir et que leur engagement dépendra des vœux des patients (Mitchell, 1999).

Un sixième aspect de l'acquisition des connaissances a été ajouté au modèle conceptuel qui oriente la réflexion sur la pratique que l'on a appelé "méconnaissance" ["unknowing" en anglais]. Ainsi, l'infirmière a conscience qu'elle ne connaît pas et ne peut jamais pleinement connaître la perspective du patient (Munhall, 1993). L'incorporation de cet élément de méconnaissance au modèle revêtait une grande importance pour les infirmières Interlink, car il leur permettait de décrire la composante humaniste de leur pratique comme étant une forme particulière de prestation de soins qui dépasse le domaine strictement médical, et il empêchait de réduire les cas à la simple analyse de leurs éléments empiriques. Les infirmières Interlink reconnaissent que la dispensation de soins de nature humaniste s'accompagne d'un élément de méconnaissance. Ce dernier exige de l'infirmière qu'elle écoute activement son moi et qu'elle soit prête à développer ses connaissances sur l'interaction entre le patient et elle-même afin d'améliorer les soins et le soutien dispensés. La pratique professionnelle exige qu'elle se sente à l'aise avec l'inconnu à la lumière d'un vaste fonds de connaissances et de la compréhension du vécu de la personne aux prises avec le cancer.

Tableau Un: Modèle pour la réflexion structurée (10^e version)

Modes d'acquisition du savoir de Carper	Questions guidant la réflexion
Dim. esthétique	L'art des soins infirmiers Qu'est-ce que j'essayais d'accomplir? Quels sentiments le patient m'a-t-il décrits? Pourquoi ai-je réagi comme je l'ai fait? Quelles en ont été les conséquences?
Dim. personnelle	Qu'ai-je ressenti dans cette situation? Par quels facteurs internes, systèmes de croyances ou valeurs ai-je été influencée?
Dim. éthique	Dans quelle mesure mes actions correspondaient-elles à mes croyances? Quels principes éthiques étaient en jeu?
Dim. empirique	Quelles connaissances auraient dû m'éclairer? Quelle théorie aurait pu m'aider à décrire la situation? Sur quelles données probantes reposent les interventions utilisées?

Version anglaise reproduite avec la permission de Johns (1995).

Le tableau deux décrit le modèle de réflexion adopté par les infirmières Interlink lequel incorpore les six modes d'acquisition des connaissances ainsi que les questions dont elles se servent pour orienter leur réflexion.

Utilisation du cadre de réflexion

Lorsqu'elle utilise le cadre de réflexion, l'infirmière Interlink choisit un patient auquel elle a prodigué des soins dans le cadre de sa pratique et elle se penche sur les soins qu'elle lui a dispensés. Elle peut choisir d'examiner seulement un des éléments du cadre de réflexion ou bien l'ensemble des éléments étant donné que certaines relations infirmière-patient exigent que l'attention porte sur des éléments particuliers. Les infirmières pour qui la démarche d'auto-réflexion est encore une nouveauté préfèrent examiner tous les éléments du cadre.

Lorsqu'elle effectue sa démarche de réflexion, l'infirmière présente un cas particulier à l'équipe infirmière Interlink qu'elle fait suivre d'une réflexion sur les soins prodigués structurée au moyen du cadre. L'infirmière prépare sa réflexion avant de la présenter à l'équipe; elle a donc eu l'occasion de recenser la littérature à la recherche de renseignements supplémentaires qui auraient pu *rehausser sa pratique*. La réflexion portant sur l'aspect empirique de l'acquisition du savoir infirmier peut amener l'infirmière Interlink à explorer plus à fond un concept ou un construit théorique particulier qui pourrait être utilisé pour améliorer sa pratique. Par exemple, une infirmière Interlink a passé en revue les écrits sur l'adaptation afin d'éclairer sa pratique de manière empirique dans le cas d'une femme éprouvant une détresse importante face à son diagnostic de cancer du sein. Une fois que l'infirmière a terminé sa présentation, l'équipe et une facilitatrice (la Responsable du développement de la pratique) en font une exploration avec l'infirmière et lui fournissent des

commentaires sur sa pratique en l'orientant vers des connaissances additionnelles ou en lui donnant des conseils pratiques qui auraient pu éclairer sa pratique et pourraient s'avérer utiles dans de futures interactions patient-infirmière. On trouvera ci-dessous un extrait d'une présentation de réflexion sur la pratique.

Réflexion concernant un cas de soins

L'infirmière rapporte l'histoire de Sally, une femme qui n'a pas loin de 80 ans et qui reste farouchement et fièrement autonome. Cela fait des mois qu'elle se plaint auprès de son médecin de famille de constipation et de plénitude abdominale générale. En fin de ligne, elle se retrouve au service des urgences présentant des saignements vaginaux et une obstruction abdominale. Une opération immédiate révèle un diagnostic de cancer de l'ovaire de stade III. Elle passe ainsi plusieurs semaines à l'hôpital, la plupart d'elles dans l'unité de soins intensifs. Gravement malade, elle a failli mourir. Elle ne se souvient pas clairement de cette période mis à part un commentaire du chirurgien qui lui annonçait qu'il "avait tout enlevé". Sally a hâte de retourner chez elle, mais elle commence à s'inquiéter et à se sentir frustrée quand elle ne retrouve pas sa santé et son énergie d'antan dans la semaine suivant son congé. Moins d'un mois plus tard, elle fait des cauchemars sur son séjour à l'hôpital. Elle refuse l'aide d'un psychiatre. Durant ces jours-là, elle ne veut pas croire qu'on l'a totalement débarrassée de son cancer et elle croit que les docteurs ne lui disent pas tout et qu'ils minimisent ses inquiétudes. Elle concentre ses efforts sur le rétablissement de ses forces d'antan et elle tient à remonter sur son triporteur qui symbolise son autonomie. On lui offre l'aide d'une thérapeute occupationnelle œuvrant en santé mentale communautaire, mais cela ne sert à rien. Durant tout ce temps, elle continue de penser qu'elle souffre encore du cancer car la constipation ne s'est point arrêtée (les radiographies et les examens par IRM s'avèrent négatifs).

La réflexion de l'infirmière

Dimension esthétique. J'avais de nombreux désirs pour Sally. Je voulais que cessent ses souvenirs pénibles et ses cauchemars effrayants. Je voulais qu'elle ressente moins d'impatience et d'effroi envers sa fatigue, qu'elle se fasse confiance pour l'utilisation de son triporteur et qu'elle soit capable de sortir de son appartement en toute autonomie. Je souhaitais qu'elle reprenne ses activités sociales. C'était ce que Sally m'avait dit qu'elle désirait. J'ai saisi l'angoisse qui marquait sa confiance la plus révélatrice: "Je n'avais jamais pensé que je deviendrais malade et que je mourrais un jour...". Je sentais la profonde relation qui me liait à elle et je désirais alléger son angoisse. Je voulais qu'elle sache que je croyais ce qu'elle disait et que je voulais l'aider. Je pensais que je m'étais ouverte à Sally grâce aux rapports étroits que j'entretenais avec elle et grâce à mon intention de lui venir en aide. Il fallait que je fasse l'effort de ne rien dire, de l'écouter, de débarrasser mes pensées de tout programme. Johns (1995) nous explique que la dimension esthétique de l'acquisition des connaissances est au centre du savoir infirmier et qu'elle est éclairée par les dimensions empirique, personnelle et éthique de la pratique. Dans ma relation avec Sally, la dimension esthétique était la compréhension de l'angoisse qu'elle ressentait après avoir réalisé et admis sa vulnérabilité et sa mortalité.

Dimension personnelle. Plutôt que d'écouter véritablement et d'accompagner Sally dans son angoisse, je me suis mise à essayer de régler ses autres problèmes. Je l'ai abandonnée à son angoisse qui n'a fait qu'augmenter car mes interventions ne donnaient pas de bons résultats. Le but ou "résultat" que j'envisageais – qu'elle retrouve le plus de son autonomie précédente – était aussi le but de Sally. Pourtant, si j'avais bien compris la portée de ce que je savais – que Sally voulait se débarrasser de cette angoisse et qu'elle avait l'habitude de prendre soin d'elle-même – j'aurais abordé Sally en tant qu'être humain ayant bien des questions et des inquiétudes semblables aux miennes à propos de la vulnérabilité et de la mortalité. Nous aurions toutes deux appris quelque chose au sujet de nous-mêmes et de l'autre (Parse, 1998). Il se pourrait – ou non – que Sally

Tableau Deux: Cadre de réflexion des infirmières Interlink

Modes d'acquisition	Questions guidant la réflexion
Dim. esthétique	L'art des soins infirmiers Qu'est-ce que j'essayais d'accomplir? Quels sentiments le patient m'a-t-il décrits? Pourquoi ai-je réagi comme je l'ai fait? Quelles en ont été les conséquences?
Dim. personnelle	Qu'ai-je ressenti dans cette situation? Par quels facteurs internes, systèmes de croyances ou valeurs ai-je été influencée?
Dim. éthique	Dans quelle mesure mes actions correspondaient-elles à mes croyances? Quels principes éthiques étaient en jeu?
Dim. empirique	Quelles connaissances auraient dû m'éclairer? Quelle théorie aurait pu m'aider à décrire la situation? Sur quelles données probantes reposent les interventions utilisées?
Dim. sociopolitique (White, 1995)	Où et comment puis-je faire entendre ma voix? Quelle action inductrice de changement est nécessaire pour répondre à ces besoins des patients?
"Méconnaissance" (Munhall, 1993)	Qu'est-ce qui ne peut s'expliquer dans la situation du patient et tient tout simplement à la façon d'être de la personne

Adapté avec la permission de Johns (1995).

se déplace en triporteur ces temps-ci. Ce qu'elle fait en ce moment ne paraît pas important. Car ce qu'elle fait et ce qu'elle éprouve est moins sous la marque de l'angoisse et plus sous celle de la confiance et de l'espoir (et ce, en dépit de son infirmière et de ses bricolages). Et elle continue de m'aider à apprendre et à découvrir de nouvelles choses dans ma relation avec elle.

Dimension éthique. C'est encore la réflexion qui m'a aidée à comprendre que ce sont les questions sur le savoir éthique qui m'ont permis de réaliser que j'aurais pu accompagner Sally si je l'avais respectée en tant qu'experte sur sa propre vie et si je m'étais ouverte à Sally en tant qu'être humain, et en tant qu'être humain qui ne possède pas toutes les réponses. Mes actions ne correspondaient pas à mes croyances. C'est selon ma propre perspective que je m'efforçais de régler les problèmes pour Sally. Et j'ai mis bien du temps à découvrir la perspective de Sally; en fait, la question du triporteur n'était pas d'importance majeure pour elle. Elle se préoccupait plutôt du fait qu'elle avait été gravement malade, qu'elle en était presque morte et qu'elle n'avait pas encore retrouvé le plein contrôle de sa vie. Une approche éthique des soins aide l'infirmière à fournir une présence empreinte de compréhension aux patients et à entendre leur perspective et les façons dont ils veulent faire face à la maladie qui les frappe.

Dimension empirique. Pour soigner Sally, je dois pouvoir me laisser guider par une perspective théorique plus proche de l'approche humaniste. J'ai examiné les écrits qui portaient sur les réponses infirmières humanistes à des réactions de patients complexes, notamment la "Human - Becoming Theory" de Parse (Parse, 1998). Grâce à Sally, j'ai appris que je pouvais porter attention aux pas en avant et en arrière – aux ambiguïtés et aux contradictions – dans les conversations. La théorie de l'adaptation m'a également aidée à comprendre les réactions traumatiques précoces de Sally à l'annonce du diagnostic telles que ses cauchemars et l'agitation qu'ils créaient en elle.

Dimension sociopolitique. Pour cette situation de pratique, la réflexion ne visait pas la dimension sociopolitique. Cependant, dans d'autres situations, l'infirmière aurait pu s'interroger sur le changement systémique ou sur l'activité de défense des intérêts des patients qui pourraient être nécessaires pour fournir du soutien aux personnes atteintes de cancer et soignées à domicile. La défense des intérêts peut amener l'infirmière à aider d'autres personnes à entendre et à comprendre la perspective du patient.

Méconnaissance. J'ai réalisé que je ne saisisais pas entièrement le vécu de la personne aux prises avec le cancer, et je reconnais que j'ai besoin de m'ouvrir à l'autre et d'entendre son histoire et sa perspective. Il faut que j'écoute activement. Je voulais que Sally sache que les médecins et moi, nous prêtions attention à elle afin qu'elle se croie en bonne santé et qu'elle se concentre sur sa vie. Lorsque j'établissais des buts avec Sally concernant son rétablissement, j'étais assaillie d'une agitation intérieure car je connaissais les probabilités de récurrence de son cancer. Je voulais l'aider à poursuivre sa vie quotidienne. Pour l'aider dans ce cheminement et pour comprendre sa perspective, je lui ai posé un certain nombre de questions d'évaluation du genre: "Qu'est-ce que vous espérez qu'il vous arrive? De quelle aide avez-vous besoin pour cela?" Ces questions engendraient une immense anxiété chez Sally. Elle me demandait de l'aider, de l'orienter et puis elle rejetait les idées avancées. Elle exprimait ses sentiments et ses frustrations, mais à toutes les suggestions proposant des pistes de résolution de problèmes, elle répondait en disant: "Je ne veux pas en parler". Les confidences de Sally entrecoupées de blocages me frustraient. J'ai accordé la priorité à l'écoute et je lui ai posé moins de questions. Toutefois, je n'articulais pas ma frustration – ni même la reconnaissais consciemment. J'ai perdu les priorités de vue. Je voulais être présente auprès de Sally pour elle et selon sa propre perspective et je crois être ouverte à ce genre de pratique. Je crois sincèrement que c'est ainsi que je façonne ma pratique. Pourtant, sans

m'en rendre compte, j'écoutais mon propre programme, et c'est ainsi que je me suis mis dans la tête de régler les problèmes reliés à cette situation.

La capacité de l'infirmière à réfléchir sur sa pratique dans une situation comme celle-ci donne des aperçus intimes des approches qu'elle utilisait dans sa pratique et lui permet d'explorer des approches de pratique et de dispensation de soins plus efficaces.

S'adonner à la réflexion sur la pratique

La connaissance de soi et l'auto-réflexion de l'infirmière représentent les deux éléments les plus difficiles à incorporer aux séances de réflexion sur la pratique qui sont offertes à l'ensemble des membres de l'équipe infirmière Interlink. Et pourtant, ils constituent deux des moyens les plus positifs de rehausser les relations avec les collègues et les patients. La dimension personnelle ou connaissance de soi a trait à l'expérience intérieure d'où émerge la personne entière d'une conscience accrue, et c'est par le truchement de cette connaissance de soi que l'on est à même de comprendre autrui (Chinn et Kramer, 1995).

L'auto-réflexion est un puissant outil qui améliore la compréhension de soi et révèle les raisons du comportement de l'infirmière et les obstacles éventuels à la relation thérapeutique. Les résultats d'une intervention infirmière dépendent nettement de la sorte de personne qu'est la praticienne, et l'infirmière doit avoir conscience de qui elle est afin que les préoccupations d'ordre personnel n'entravent pas l'exploration par le patient de ses propres inquiétudes (Johns, 1995). Certes, le fait de s'impliquer dans une démarche d'auto-réflexion, de révéler la dimension personnelle dans une situation de santé, pourra intimider l'infirmière.

La réflexion sur la pratique donne aux infirmières l'occasion d'articuler les stratégies comportementales qui sous-tendent les interactions et qui les éclairent sur leurs propres schémas de comportement interpersonnel. La perception de ses propres sentiments revêt une importance capitale si on veut comprendre et accepter le patient ou son proche sans préjugés, particulièrement dans un milieu caractérisé par la diversité culturelle. Cependant, il faut reconnaître que la démarche d'auto-réflexion crée un sentiment de vulnérabilité chez l'infirmière car elle abandonne les obstacles liés au rôle professionnel et elle révèle, à ses collègues et à elle-même, sa façon d'exercer. Mais ce n'est que par le truchement d'une démarche d'auto-réflexion que l'on peut résoudre les différences entre les barrières professionnelles et les limites personnelles dans chaque relation infirmière-patient.

Façonner un environnement propice à la réflexion sur la pratique

La promotion et la mise au point d'un environnement propice à la réflexion font du vécu des infirmières une source d'apprentissage. Les infirmières Interlink sont prêtes à s'impliquer davantage dans l'auto-réflexion et dans la réflexion soumise à l'évaluation des pairs. Dans leur cas, l'utilisation de la réflexion sur la pratique au cours des réunions mensuelles de l'équipe infirmière a été un processus lent qui a suivi le rythme du développement des rapports entre les membres de l'équipe. L'orientation du processus a grandement bénéficié de la présence d'une facilitatrice expérimentée qui n'est pas une praticienne Interlink. Le rôle de la facilitatrice est de fournir orientation et rétroaction à l'infirmière individuelle qui utilise le cadre de réflexion sur la pratique et aux membres de l'équipe afin de les encourager à fournir, à leur collègue, des commentaires francs et constructifs. Durant les tout premiers mois, les collègues ont eu tendance à ne donner qu'une rétroaction positive, mais elles sont dorénavant plus à l'aise pour mentionner des interventions qui auraient pu être utiles. L'environnement a été créé graduellement au sein de l'équipe infirmière, et ses membres sont passés d'une réflexion timide sur leur pratique à l'articulation de suggestions d'interventions de rechange.

Les infirmières Interlink ont éprouvé divers degrés de gêne et d'excitation. Un climat de confiance est d'importance critique si on veut dépasser l'étape du simple soutien accordé aux interventions des collègues pour atteindre une réflexion véritable sur les décisions et les interventions retenues dans la pratique et pour explorer de nouvelles approches possibles de la pratique.

La réflexion sur la pratique exige que l'on remette en question ses croyances anciennes sur les attitudes et les rôles professionnels. Ainsi, les barrières reliées au rôle professionnel peuvent restreindre notre habileté à créer des rapports humanistes et personnels avec les patients. La relation infirmière-patient est un type de relation entre deux personnes, mais elle est plus complexe et elle exige que l'infirmière ait conscience des limites de l'espace personnel si elle veut favoriser la valeur thérapeutique de sa pratique. Par exemple, nous sommes très présentes auprès des patients affligés, il nous arrive même de pleurer avec eux, mais nous ne sommes pas pour autant accessibles durant nos heures hors travail. Lorsqu'elle éprouve des liens affectifs avec les patients – qu'il ne faut pas confondre avec l'engagement affectif – l'infirmière risque d'être peinée par la récurrence de la maladie ou par le décès de patients. En confessant de tels liens affectifs avec les patients à des collègues dans le cadre d'une séance de réflexion sur la pratique, les infirmières peuvent être nombreuses à penser qu'on risque de critiquer leur manque d'efficacité professionnelle.

Il ne faut pas voir dans la réflexion sur la pratique une méthode d'identification des lacunes au niveau de la pratique, mais plutôt un moyen de rehausser notre compréhension de l'art et des connaissances sous-tendant les soins aux patients et à leurs proches et des manières d'améliorer ces soins. Les infirmières chefs et les collègues doivent créer un climat de respect mutuel favorisant un sentiment de confiance et de sécurité afin de minimiser le sentiment de vulnérabilité qui naît obligatoirement de la révélation des façons dont on travaille avec les patients.

Le pouvoir de la réflexion

L'un des aspects les plus intimidants de la mise en place d'une démarche de réflexion structurée est d'empêcher qu'elle ne devienne un exercice purement intellectuel. Car la réflexion sur la pratique

permet éventuellement de révéler et d'articuler les connaissances essentielles sous-tendant la pratique infirmière et d'articuler l'art de la dispensation des soins. On a dit de la réflexion sur la pratique qu'elle était à la fois excitante et terrifiante. Fay (1987) voit dans la réflexion un processus de révélation, d'habilitation et d'émancipation. Par révélation, on entend se comprendre soi-même dans le contexte de la définition et de l'assimilation de la pratique; l'habilitation, c'est avoir le courage et la détermination de prendre les mesures nécessaires pour changer intérieurement; quant à l'émancipation, elle consiste à se libérer de ses anciennes manières d'être et à devenir la personne que l'on doit être pour atteindre les buts fixés en matière de pratique. Pour les infirmières Interlink, la pratique de l'auto-réflexion est une révélation, et elles s'engagent sur la voie de l'habilitation et de l'émancipation.

Conclusion

L'image de l'infirmière de demain est celle d'une spécialiste du savoir, capable d'articuler les connaissances qui orientent la prise de décision. Les infirmières Interlink trouvent qu'un cadre conceptuel guide leurs pas à mesure qu'elles adoptent la réflexion sur la pratique. Parfois, il leur a été difficile d'explorer en profondeur les situations de patients. Cependant, cette démarche a revêtu une grande importance pour le développement de la qualité de la pratique des infirmières Interlink, et elle a contribué à leur développement individuel et à leur croissance au sein de l'équipe. Il est possible que les infirmières aient besoin d'un certain temps pour perfectionner les compétences liées à la réflexion et d'une longue période de pratique pour intérioriser les signaux issus de la réflexion comme façon de considérer la pratique. Les infirmières à qui on ne donne ni orientation ni encadrement peuvent éprouver des difficultés à atteindre la contemplation et douter de leur capacité à examiner la situation en profondeur, à considérer les raisons de leurs pensées, sentiments et actions. On favorise la réflexion sur la pratique par le biais d'environnements qui offrent à l'infirmière une orientation et un encadrement tandis qu'elle chemine dans cette voie. Les infirmières Interlink s'engagent à utiliser la réflexion en vue de faire progresser constamment la qualité des soins qu'elles dispensent et d'articuler leur rôle en influençant de manière positive le vécu des personnes atteintes de cancer. 

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The impact and management of cancer-related fatigue on patients and families

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Abstract

Fatigue has been identified as both a chronic and recurrent problem for individuals diagnosed with and treated for cancer, yet there is little information on how to manage the impact of fatigue. Describing what happens to individuals and their families as a result of fatigue and identifying what individuals do to manage or reduce the impact of fatigue are essential elements in determining multidimensional nursing interventions. The purpose of this pilot study was to examine the impact of fatigue on individuals with cancer of the lung and their families, and explore how they managed as a result of the fatigue. A semi-structured interview guide was used with 22 lung cancer patients and 14 family members six weeks post completion of radiation therapy.

Results indicated that fatigue was not reported as a major concern by many of the participants in this study. For those who did experience fatigue, it was considered an inconvenience and a frustration that had to be dealt with for a limited time period. Some patients appeared to gradually adjust and accommodate to the fatigue and were not really aware of the changes that took place over time. Over half of the family members felt more of the impact of fatigue than did their loved ones. Family subtly assumed or took over responsibilities and activities the patient could no longer perform.

The symptom of fatigue has been well documented in the cancer experience as both a chronic and recurrent problem for individuals diagnosed with and treated for cancer. The emphasis of previous work has been on deriving a conceptual definition of fatigue, achieving consensus on a definition, and developing theoretical frameworks to guide further study of this complex construct. Fatigue has been conceptualized as a multidimensional phenomenon, attributable to multiple causes and having a negative effect on quality of life (Piper, 1993; Tiesinga, Dasson, & Halfens, 1996). Describing what happens to individuals and their families as a result of fatigue and identifying what individuals do to manage or reduce the effects caused by the fatigue are essential elements in determining multidimensional nursing interventions.

Fatigue in chronic illness

Fatigue has been documented in chronic illnesses other than cancer. The major focus of this existing research has centred on determining the severity, duration (acute/chronic), frequency, and associated symptoms of fatigue (Hait, 1978; Packer, Foster, & Brouwer, 1997; Srivastava, 1989), identifying correlates of fatigue (Belzar, Henke, Yelin, Epstein, & Gillis, 1993; Crosby, 1988; Krupp, Larocca, Muir, & Steinberg, 1990), and describing the relationship between fatigue and depression (Cardenas & Kutner, 1982; Jamar, 1989; Krupp et al., 1990; Krupp, Larocca, Muir-Nash, & Steinberg, 1989; Pickard-Holley 1991; Srivastava). Although beginning work has been done to relate the severity of symptoms experienced to the effect of fatigue on activity levels, the trend has been to use traditional performance status measurements rated by health professionals, predominantly in institutional settings (Packer, Sauriol, & Brouwer, 1994). This approach has limited relevance today, and the narrow focus of these indicators on the basis of daily tasks negates the social and role responsibilities of daily life. Fisk et al. (1994) reported that the self-rated impact of fatigue was related to the amount of time per day patients were fatigued. Furthermore, the impact of fatigue was not related to disease classification and had little relationship to the clinical

ABRÉGÉ:

L'IMPACT, SUR LES PATIENTS ET LES PROCHES, DE LA FATIGUE ASSOCIÉE AU CANCER ET SA GESTION

Il est reconnu que la fatigue est un problème à la fois chronique et récurrent chez les personnes diagnostiquées d'un cancer et suivant un traitement, mais il existe peu d'information sur la gestion de l'incidence de la fatigue. La description des répercussions de la fatigue chez les personnes atteintes et leurs proches et la détermination de ce qu'ils font pour en gérer et en réduire l'incidence représentent des éléments essentiels de l'élaboration d'interventions infirmières multidimensionnelles. Cette étude pilote visait à examiner l'incidence de la fatigue chez les personnes atteintes de cancer du poumon et chez leurs proches et à explorer les façons dont ils s'adaptaient à cette fatigue. On a utilisé un guide d'entrevue semi-structurée auprès de 22 patients atteints de cancer du poumon et de 14 proches six semaines après la fin du traitement de radiothérapie. Les résultats indiquaient que les participants à l'étude étaient peu nombreux à signaler la fatigue en tant que préoccupation majeure. Chez ceux qui indiquaient l'avoir éprouvée, la fatigue était perçue comme une complication et une frustration auxquelles ils ne devaient faire face que durant une période de temps limitée. Certains patients semblaient s'adapter graduellement à la fatigue et ils n'étaient pas vraiment conscients des changements qui étaient survenus au fil du temps. En revanche, plus de la moitié des proches avaient éprouvé l'incidence de la fatigue plus que ne l'avaient les patients. C'est de manière subtile que les membres de la famille assumaient les responsabilités et effectuaient les activités que les patients étaient obligés d'abandonner.

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variables of neurological impairment and the time since self-reported onset of disease symptoms. The disruption in one's life was not symptom-specific, but was related to the ability to accommodate the fatigue and the resulting effect on mental well-being regardless of the degree of physical impairment. This finding was also supported by the work of Wagenaar (1995). Absent in the fatigue and chronic illness literature was the perceived effect of fatigue on the family.

Fatigue and cancer

Recognition of fatigue as one of the major components for study in quality of life research has been accomplished through the development of theoretical frameworks to understand the concept (Piper, Lindsey, & Dodd, 1987; Winningham et al., 1994), and the development of psychometric instruments for testing theory and identifying influencing factors of fatigue (Graydon, Bubela, Irvine, & Vincent, 1995; Irvine, Vincent, Graydon, Bubela, & Thompson, 1994; Piper, 1989). Fatigue in individuals with cancer has been studied by examining levels of activity (Glaus, 1993; Pickard-Holley, 1991), energy conservation and restoration (Pickard-Holley; Piper et al.), the influence of various treatment modalities on the severity of fatigue (Christensen & Kehlet, 1993; Nail & King, 1994), the negative outcome for quality of life (Irvine, Vincent, Bubela, Thompson, & Graydon, 1991), ability to maintain self-care (Rhodes, Watson, & Hanson, 1988), and the effect on depressive states (Pickard-Holley). Changes in biological and psychological patterns have also been reported as factors which influence the signs and symptoms of fatigue (Piper, 1988; Piper et al.). Cancer-related fatigue increases over the course of treatment with both radiation therapy and chemotherapy and also along the disease trajectory (Bruera & MacDonald, 1988; Graydon, 1994; Irvine et al., 1994; Jamar, 1989). Fatigue after surgery is particularly relevant to cancer patients who receive adjuvant therapy, as they may not have completely recovered from surgery when the next therapy begins. The possible cumulative effects of sequential treatments may increase fatigue.

The impact and management of fatigue

There is scant literature to assist nurses in improving their understanding of the impact of fatigue on the lives of patients with cancer and their families. Fatigue has been identified as either one of the worst or the worst symptom by patients with systemic lupus erythematosus (SLE) and multiple sclerosis (MS) (Fisk et al., 1994; Krupp et al., 1990; Wagenaar, 1995), and is consistently described by cancer patients as one of their most distressing symptoms (Knobf, 1986; McCorkle & Quint-Benoliel, 1983; Munkres, Oberst, & Hughes, 1992; Nail & King, 1994). The nature of the distress experienced due to fatigue in cancer patients is unknown. The most common fatigue management efforts are aimed at restoring and conserving energy and taking one's mind off fatigue through distraction. Winningham et al. (1994) have recommended that fatigue management include education, attention-restoring activities, and exercise.

Purpose of study

The purposes of this pilot study were to examine the impact of fatigue on individuals with cancer of the lung and their families, and to explore how fatigue was managed.

Conceptual framework

The study was guided by a conceptual model of symptom management comprised of three interrelated dimensions: the symptom experience, symptom management strategies, and symptom outcomes (Larson et al., 1994). This model assumes that symptoms need to be managed and such management should be

aimed at influencing the symptom experience, not just the outcome. Symptom experience refers to the dynamic interchange among perception of symptoms which includes personal, environmental (social, physical), and health/illness status; evaluation of the meaning of a symptom including one's judgment about that symptom and the threat imposed and the response to symptoms which may be physiological, psychological, or behavioural. Symptom management strategies require a patient-family-health provider partnership that is complementary and encourages patient and family management of the symptom. Symptom management is often fluid, with strategies changing over time to maintain effectiveness.

Method

Design

A content analysis methodology (Downe-Wamboldt, 1992) was used to systematically describe the experience of cancer-related fatigue for patients and family members.

Participants

The sample consisted of two groups, the individual with lung cancer and a designated family member. Patients were asked to identify an individual who lived with them and who they considered to be a close family member, and who could best represent the family's experience of the impact of the cancer-related fatigue. In the event that the person lived alone or with a friend, the identified family respondent was whomever was considered most familiar with the impact the fatigue had on the person's life and home.

A purposive sample of individuals diagnosed with primary, non-small cell inoperable lung cancer without distant metastases, i.e., Stage III disease (CTRF, 1996), and who were receiving radiation to their thorax only, was accrued for the study at the completion of radiation treatment. This was done through the radiation department and the follow-up clinics designated for lung cancer at the Nova Scotia Cancer Clinic in Halifax. A mutually convenient time for the interview was arranged with the individual and their family member six weeks post completion of radiation therapy. Patients had to be between 18 and 70 years old and have a family designate who would agree to participate.

Procedure

Ethical approval to conduct the study was obtained from the Queen Elizabeth II Health Sciences Centre Research and Review Committee. Potential participants were identified by the clinic staff who approached the patients, informed them of the study, and invited interested individuals to meet the researcher. Informed consent was obtained by the researcher. The interviews were conducted by one of three interviewers from the research team at a mutually agreed upon time either at the clinic or in the participant's home.

Semi-structured interview guide

A semi-structured interview guide was developed by the research team specifically for use in this study. The content of the questions reflected the clinical experiences of the research team members (six with many years of oncology nursing experience), recent graduate work completed by a member of the team which involved indepth interviews of a different patient population experiencing fatigue (Wagenaar, 1995), and the literature on fatigue in chronic illness, specifically cancer. The development of the interview questions was guided by the conceptual framework. As well as asking about the changes they had experienced physically, and in their day-to-day activities, the scope of the questions went beyond role responsibilities to include participants' feelings, relationships with family and friends,

intimacy issues, and social changes. The questions sought to explore how patients and family adjusted to the impact of the experience rather than just the actual symptom of fatigue. Patients were asked how the fatigue affected their relationship with others, and how they would describe their feelings about being fatigued. They were asked what they did to keep these changes from affecting their lives in these ways, and, what or how they found the approaches helpful. For example, questions included, "Fatigue can influence your mood and feelings. How would you describe your feelings about being fatigued? How do you manage/control these feelings? Of the things you do, what do you find helpful?"

Family members were interviewed separately. They were asked about the changes they had experienced because of their loved one's fatigue, what they (the family members) did to keep these changes from affecting their lives, and if they found it helpful. For example, "How has your mother's fatigue affected your relationship with others? What do you do to keep your mother's fatigue from affecting your relationship with others? Of the things you do, what do you find helpful?"

The interview guide was pilot tested for content validity with five oncology nurses working in lung cancer care, five patients with lung cancer, and a support group of individuals with SLE available to the research team. The interview process was conducted in the same manner for both the person with cancer and the family designate. All interviews for the pilot testing and the study were taped and transcribed verbatim. Interviews took from 10 to 40 minutes.

Data analysis

Content analysis was used to analyze the findings of the semi-structured interviews. Data were analyzed using phrases, sentences, or paragraphs that referred to the fatigue experience. The data were searched for themes or ideas contained within the respondents' answers which determined and defined mutually exclusive categories for our category system. Information obtained from one particular question was accepted to answer other research questions when applicable. The unit of analysis was coded in its content category regardless of where in the transcript it occurred. Sentences or phrases that included the words 'because' or 'but' were analyzed as a complete thought. When a sentence contained 'and/or,' it was considered a separate unit of analysis. Category frequencies were tabulated using all responses. Each unit was counted only once. The categorization system was developed by three of the investigators. Throughout the analysis, samples of the text were tested to determine if the rules and classifications were clear and distinct. Categories were reworked as needed. Ninety-five per cent reliability agreement was achieved for coding of the data.

Results

Sample

The sample consisted of 22 patients with non-small cell lung cancer; 12 males and 10 females between the ages of 46 and 80, with an average age of 66 years. Of these 22 patients, 13 were married, five were divorced, three were widowed, and one was single. Three had completed their high school diplomas and four had university degrees. Fifteen lived with a spouse (partner) and six of these patients still had children living in the home. Three lived alone, three with a friend/roommate, and one lived with children.

No patient was actively working, although two stated that they were on sick leave. All patients had smoked prior to their diagnosis and just over half continued to smoke at the time of the interview. Of the 15 people who consumed alcohol pre-diagnosis, nine had stopped post-diagnosis. Symptoms did not appear to be a concern for these

participants, as less than 10% experienced pain and 81% reported that they were not experiencing any symptoms.

Twenty-three family members were accrued into the study, but four were not interviewed because their scheduling would not permit it. The 18 family members who completed the interviews were comprised of wives (n=6), husbands (n=4), daughters (n=5), son (n=1), nephew (n=1), and close friend (n=1). Four transcripts were deleted from the analysis because the respondents were unable to answer the questions about the patient (i.e. did not know patient well enough), resulting in a total sample of 14 family members.

The impact of fatigue on patients

Patients discussed a variety of aspects of their lives which were impacted by fatigue (see Table One).

Physical, cognitive and behavioural impact. The greatest impact that fatigue had on patients was the physical, cognitive, and behavioural changes that they experienced. "I just was more quiet" (when fatigued). Patients reported having to take naps or rests, and sleeping throughout their day, all of which were changes from previous patterns. "I don't have any problem going in and lying down on the bed and having an hour's sleep, be it 10 in the morning or two in the afternoon." Other changes included the inability to do usual household activities, limitations in walking/climbing stairs, and having to move and think more slowly. "...you can't do things like if I wanted to vacuum I just am physically unable to get the vacuum cleaner out and do it, that, or if I do it then I would get so tired." "I just slow down a bit."

Emotional impact. Participants described the emotional experience of being fatigued in negative tones. Many reported being frustrated, apathetic, unhappy, or upset. "It wasn't moody as much as frustrating." "I didn't care if I did anything, so I didn't care if I was tired." "It was hellish for about four weeks; you aren't as joyful." "...it upset me a little bit."

Changes in family life and relationships. Patients reported a range of changes involving loved ones due to their fatigue. "The help that they gave me was more important than money." Patients described how family respondents had to "take over" household and yard duties normally performed by the patient. "...he does most of the bull work or heavy work now." "Lying around the house...bothers the wife I think." Some patients reported that as a consequence of fatigue, they felt closer to loved ones, and although sexual intercourse was not occurring, intimacy had improved. "It's like we are in this together...but the intimacy has been great...a lot more closeness and hugging and touching and

Table One: Impact of fatigue on patients (n=22)*		
Patient impact	Number of patients	Frequency impact reported
Personal		
• Physical, cognitive and behavioral	18	65
• Emotional	16	82
• No Impact	3	4
Family		
• Family life and relationships	11	52
• No impact/no changes	8	15
Social		
• Activities, friendships, leisure	9	24
• No Impact	8	10
* numbers do not always add up to 22 because not everyone answered every question		

affection.” Patients reported that family members were performing some of the patients’ personal hygiene, driving them instead of “letting” the patient drive themselves, and family members were not letting them be alone. Eight patients reported that there was no change in or impact on family life when they were initially asked. Three of the patients who responded in this category indicated that family understood the fatigue, “...he knows that I’m sick and that I just couldn’t do some of the things that I wanted to do or needed to do.” Three others indicated that family did not understand, “They just say, you should phone up and find out what’s wrong.”

Changes in social activities, friendships and leisure activities. Fatigue impacted people’s ability to maintain a normal social life. Patients talked about no longer feeling able to go to dances or parties or to play bingo. “I used to go to my bridge club and go to an exercise, which I couldn’t do.” Patients reported that socialization with friends and family in bars or restaurants was either discontinued or decreased. “I used to be there every night because I knew the crowd.” Patients reported that friendships had changed because they could no longer play their usual sports with friends, or go to sports events with buddies. “We had plans for going camping; that’s on hold.”

No impact. Ten of the 22 patients who participated in the study initially stated that they had not experienced fatigue in any aspect of their lives and, therefore, had not experienced any changes or consequences from it. With further probing, however, seven of these 10 individuals began to talk about changes they had experienced, which they then attributed to the effects or consequences of fatigue.

Patients’ fatigue management strategies

Patients described a variety of fatigue management strategies to help them manage or live with their fatigue. Some activities focused primarily on fatigue prevention and energy restoration, while others described strategies used to reduce the emotional and social impact of fatigue (see Table Two).

Table Two:
Patients’ fatigue management strategies (n=22)*

Patient strategies	Number of patients	Frequency strategy reported
Energy conservation	8	17
Energy restoration	9	14
Health maintenance	6	11
Fighting spirit	9	21
Acceptance of fatigue	13	38
No strategies identified	3	4

* numbers do not always add up to 22 because not everyone answered every question

Table Three:
Impact of fatigue on families (n=14)*

Family impact	Number of family members	Frequency impact reported
Picking up the slack	8	28
Caregiver fatigue	5	8
Worry and concern	4	8
Helplessness	3	5
Closeness	4	13
Family/social life	7	30
No impact/no changes	7	12

* numbers do not always add up to 14 because not everyone answered every question

Energy conservation. Eight patients discussed managing fatigue by conserving their energy. People described pacing themselves and slowing down their thoughts, movements, and activities. “I got to pace myself with everything I do.” “Everything slow, and don’t just do it... think it, think slow...”, “go down to the basement with the laundry and stay there.”

Energy restoration. Nine of the 22 patients described activities they used to re-energize themselves. Five people reported that taking a nap was helpful. “You get an hour or so (nap) under your belt and then you get up and you aren’t as fatigued as you were when you went down.” “I sit down for a few minutes and everything will come back.” Others noted that taking a break from different activities or relaxing for a time, such as in a hot bath, restored some of their energy.

Health maintenance. Six patients reported that leading a healthy lifestyle was helpful in managing their fatigue. Exercising, eating “good food” because “I didn’t want my health to deteriorate,” and using vitamin supplements were described as helping to keep fatigue from affecting their lives. “I have to get some good food in me.”

Fighting spirit. Just under half the patients approached fatigue as a challenge (n=9). Patients described how they did not want fatigue to “get the better of them.” “I just said I’m not going to do this (sit around), so I get up every morning and I have my shower and I put on my makeup, and I get dressed as if I’m going somewhere or someone’s coming.” “I don’t think, I just do it.” “Just keep going the way I always do, even when I’m tired, it does wear off after a while.”

Acceptance of the fatigue. Over half the patients indicated that it was helpful to acknowledge that the fatigue was present, to understand it, and to accept it (n=13). “If the floors don’t get vacuumed every week, well, so they don’t, we’ll do that when I get better.” “Why dwell on it?” Patients acknowledged their fatigue and then described their adjustment tactics. “Just go out, play cards, play something.” “I go to Tim Horton’s and talk to everybody.”

Impact of fatigue on families

Family members believed that the impact of fatigue was experienced not only by the individual being treated for cancer, but also by various members of the family. The family members who were interviewed described personal accounts of how their loved one’s fatigue had directly impacted their lives. These changes, and the resultant consequences of fatigue, are categorized in Table Three.

Picking up the slack. Over half the family respondents described taking on more household and yard responsibilities as a consequence of their loved one’s fatigue (n=8). Family members reported having to complete or be entirely responsible for chores or activities normally done by the patient.

Caregiver fatigue. Just over one-third of family members experienced personal fatigue as a result of their loved one’s fatigue (n=5). Reasons varied for the family member’s fatigue. Getting up to keep their partner company, juggling caregiving, extra household duties, and making extra trips to check on their loved one were all described. “I think I’m over compensating because I’m trying to stay with him or whatever.” Two husbands commented that they developed a greater understanding and appreciation of their wife’s role in the family and with the domestic affairs.

Worry and concern. A consequence of the patient’s fatigue was the worry and concern it created for family members. Four family respondents specifically commented that they were stressed due to worry about their loved one’s weakened state:

I worry about him, he knows that at certain times, that I usually call him and if I don’t hear from him....so he’s constantly on my mind. Is he all right? Did he get to sleep? Has he fallen? ...because I find he’s tired.

Although other respondents described being worried, the general sense of their conversations was that it was the cancer as a whole, or concerns about the future or mortality, rather than the specific symptom of fatigue that was the source of their worry.

Helplessness. Feeling helpless was another consequence of patient fatigue for three family members. Even when asked, family members could not separate feeling helpless because of not being able to do anything about the patient's fatigue, from feeling helpless about the disease and the situation that arose from it. *"You feel like you want to do something to change it, but you know you can't, you feel helpless."*

Closeness. A few family members reported a positive change as a result of their loved one's fatigue, that of a strengthened relationship. Four family respondents indicated that there was an increased closeness between them and their loved one, or between them and siblings. Most descriptions of closeness centred on the new behaviours of the person with cancer, such as being more considerate of their spouse. One woman noted that this emotional intimacy took the place of a sexual relationship:

At this point in our life, we've had sex all these years, so what, I find this much nicer now, to come home and find a note or come home and find a card from him, have him phone me from the highway and say 'look I really missed you, let's go to dinner or something,' those things mean more, it's like being courted all over, so that's nice.

In the discussions of intimacy and closeness, it appears that fatigue was not the primary causative factor for changes. Each of the four respondents who discussed their sexual relationship gave reasons other than fatigue for their lack of a sexual relationship. In two cases, sexuality had been an ongoing problem. Another felt it was inappropriate when the spouse was ill and still recovering, and in another case symptoms other than fatigue precluded sexual contact.

Family and social life. Half of the family respondents commented that their loved one's fatigue had impacted family and social life (n=7). The majority of the respondents were retired, and the greatest impact of their loved one's fatigue was on their ability to socialize or partake in their usual recreational pursuits as a couple. The resulting feeling was one of loneliness. This loneliness was not necessarily the result of a loss of social contact, but of missing the usual events with their spouse.

Families' fatigue management strategies

Family members were asked what they did to keep their loved one's fatigue from affecting the various aspects of their lives, and how they managed the feelings that came from any changes that did occur. Family members described a variety of fatigue management strategies to help them manage or live with their loved one's fatigue. Some strategies were directed at protecting or helping their loved one. Helping the patient indirectly helped them (see Table Four).

Soothing the way. Over half of the family members indicated that making life easier for their loved one helped themselves. Eight family respondents assisted patients in their energy conservation and energy restoration by *"smoothing the way."* These activities were undertaken to make life easier, reduce stress, protect, and reduce demands on their loved one. *"I think that maybe we are overprotective, but we try to shield him from any stress or need to feel obliged to do things."* Another person said:

I didn't let things become a problem, like he didn't drive, so when mom had a doctor's appointment or he had a doctor's appointment I would say, "Well I'm going to ...anyway I will just take mom in ...she might as well come with me, so therefore he wouldn't have to make the effort to go."

Other protective activities included ensuring their loved one was not alone during periods when they themselves were not present, and

that they obtained the rest they required by curtailing visitors and keeping things peaceful and quiet.

Working around fatigue. Family members talked of having to be flexible. Again, just over half the family respondents managed changes in social and day-to-day activities (n=8). *"If I have to go out I make sure that everything is all right. I'm scared she might fall... so when she is in there lying down I go out."* *"But we work around it...if he's having a good moment we'll go for a walk or we'll go for a beer or supper or something like that."* *"What we've done the last few weeks is every Sunday we go up to the flea market and we walk because it's flat, there's no hills, there is no effort, he can walk."* *"... you can't start supper right away because 'did he just go to sleep or is he ready to wake up?' so your whole life just depends on when and how he's sleeping."*

Keeping busy. This category described the approach of distraction to the event. Two female family respondents commented that they felt keeping busy helped them cope by reducing the time to *"think about things."* Whether this is a strategy used to reduce the impact of fatigue or one that was used to not think about the cancer and its implications is not clear.

Maintaining contact. The strategy of keeping some normality in life emerged. Two women indicated that they made specific attempts to maintain contact with significant others in order to combat the reduced socialization with family that occurred as a result of fatigue. *"I try to force the issue like you know, I'll make a point of getting out once a week, just my daughter and I, we go to Tim Horton's for a coffee or something, go shopping anything like that."*

Prioritizing, organizing, and planning. As some family members found it necessary to be flexible, others found it necessary to become very structured. Two men found that they had to plan and organize their daily lives in order to adapt to the increased workload at home as a result of their spouses' fatigue.

Patient and Family Education

At the end of the interview, participants were asked what information patients and families should receive if they are likely to experience fatigue as a result of treatment. Participants felt that all patients and close family members should be told in depth about the possible fatigue experience so that they would know that it was normal, should it occur. Patients (particularly women) indicated that they should be taught not to give up, to *"distract yourself," "work with it,"* and *"not to let it consume you."* They wanted others to know that *"you should not let fatigue get the better of you, you need to keep busy."* One man felt strongly that, in order to plan ahead, people should be told that they probably will not be able to perform physical labour for a period of time. Participants concluded that patients and family need to be reminded that fatigue is unpredictable, that they need to rest when their body tells them to rest, and to take care of themselves. People should be reminded that, in most cases, the fatigue will end.

Table Four:
Families' fatigue management strategies (n=14)*

Family strategy	Number of family members	Frequency strategy reported
Soothing the way	8	35
Working around the fatigue	8	41
Keeping busy	2	52
Maintaining contact	2	6
Planning, organizing, prioritizing	5	6
No impact	5	6

** numbers do not always add up to 14 because not everyone answered every question*

Participants felt that individuals needed to be prepared to ask for assistance from family or others. Some family members felt that being provided information gave them a better understanding and acceptance of fatigue as a consequence of treatment. Other family members did not feel prepared for the fatigue or for how it would impact the different aspects of their life. Three family respondents strongly related nutrition and fatigue, and indicated that they were concerned about their spouses' nutritional state and this was an area in which they could have used more information.

Limitations

Perhaps the biggest limitation of this study was that often patients could not separate responses to fatigue from other aspects of the cancer experience. Their descriptions of feelings or changes may not, therefore, be directly attributable to fatigue. This older sample (average age of 66 years) had few obligations outside the home. All but two were 'retired' before the illness. One wonders if a younger sample would have experienced a greater impact of fatigue with roles, responsibilities, and commitments of children and work. Some participants indicated that they did not think that they would have been able to have worked, even part-time, with this experience. At the time of informed consent, some family members agreed to participate then later declined at the scheduled interview, thus decreasing the number of family members to 14 participants. The sample size of this pilot study was small and therefore generalizing to older lung cancer patients receiving radiation therapy is limited. A final limitation related to the conceptual framework was noted. This framework does not address the cultural context of the symptom. This may or may not have impacted patients' and family members' coping strategies related to fatigue.

Discussion

The conceptual framework for symptom management was beneficial as it allowed for consistency in exploring the symptom of fatigue. In order to have a comprehensive understanding from the patient, we explored changes caused by the symptom and how these changes were judged, as well as exploring the feelings, thoughts, and behaviours that were experienced with the fatigue. Expectations were already set by health care professionals (that the fatigue would occur), so that the symptom occurred in the context that was perceived. Patient and family were highly involved in the management strategies and, thus, involvement of the health care system was low. The perceived experience enabled most participants to maintain a positive emotional status resulting in minimal distress overall, changes in functional status, or quality of life.

Further, findings in this study are consistent with the conceptual framework which indicates that one needs to study all who are closely involved with the experience, so that all perspectives are attained. Within this study, family members seemed to identify fatigue and its impact more than the patient. They noted changes in activities, increased nap taking, and changes in mood. They expressed both positive and negative changes in family activities and relationships that occurred as a result of fatigue. They experienced the impact of their loved one's fatigue as the need to assume role responsibilities when their family member could not manage.

By implementing the framework, an analysis of participants' responses was possible. It became evident that, for many of the patients, fatigue could not be isolated or distinguished from other aspects of the cancer experience. The cancer experience as a whole, shortness of breath, and fatigue were used interchangeably in many of the descriptions. A few patients initially said that they had no fatigue, but on further exploration they expressed changes in their activities that were in fact attributed to the fatigue. It was as if they had slowly accommodated to their fatigue, so gradually that patients did not see the subtle changes that took place over time as a result of the fatigue. Fatigue did not impact these patients to the extent that we had

expected. For those patients who talked about it, fatigue was considered a nuisance and a frustrating inconvenience, but not an incapacitating event.

Furthermore, by drawing upon the framework as a guide, it became evident that patients managed their fatigue by facing it "*head on*," many with a determination to not let it alter their activities. It did not appear that patients had spent a lot of energy worrying about the fact that they were experiencing fatigue. Families indicated that because they picked up the slack, and perhaps because they had compensated for the individual's lack of involvement in activities, patients did not realize the extent to which their day-to-day activities had gradually changed. In terms of strategies to manage fatigue, there did not seem to be any new approaches not previously described in the literature. The approaches of "*fighting back*" and "*not letting the fatigue get the best of you*" seemed to help people physically, emotionally, and socially.

Studies examining fatigue in cancer indicate that it is one of the most distressing symptoms for people (Knobf, 1986; McCorkle & Quint-Benoliel, 1983; Munkres et al., 1992; Nail & King, 1994). The authors of this study conclude that the impact of fatigue on lung cancer patients post treatment was not the serious problem one might have thought. It may be because, as we have stated, the impact was so gradual that patients did not realize the extent of the changes that had occurred. Patients in the study were also well prepared for it as a response to treatment. Rhodes and colleagues (cited in Winningham et al., 1994) suggest that realistic expectations may reduce the distress patients experience and enable them to develop self strategies and coping strategies.

Patients' fatigue management strategies reported in this study are similar to those reported in other studies examining fatigue (Rhodes et al., 1988; Winningham et al., 1994). Scheduling activities, decreasing nonessential activities, and increasing dependence on others for home management have all been previously described. It seems that the findings in all of these studies suggest that patients felt responsible for managing their own fatigue, they did not expect others to come up with solutions for how to cope. The findings of this study support the idea that preparing patients for fatigue may be helpful in how patients perceive the impact of fatigue. In other studies (e.g., Irvine et al., 1994; Johnson, Nail, Lauver, King, & Keys, 1988), researchers have concluded that educating patients about the likelihood of experiencing fatigue may reduce negative perceptions of the fatigue. This would appear to be the case in this study. Most patients felt that they had been informed and prepared for some fatigue. When change occurred, adjustments were made and patients accommodated with minimal distress.

Implications for nursing practice and research

The findings of this pilot study support the need for nurses to assess patients being treated with radiation therapy for lung cancer within the broad context of home and community supports for symptom management post treatment. The study findings also support the need for nurses to educate patients and families about fatigue, its impact, and management options. Many patients in the study had been told to expect to be fatigued, but did not appreciate the subtle changes that occurred. Instead, they expected to feel a sudden and lasting event of debilitating fatigue. Informing patients and families that there is a range of fatigue that may be experienced and the potential timeframe in which symptoms are manifested may help to normalize the experience. Furthermore, nurses need to become more aware of the new and emerging options for managing fatigue in order to assist patients and families in learning these strategies.

This pilot study suggests that fatigue was not the issue health care providers believed it might be for this particular group of lung cancer patients. The need for a larger study with more consistency in

identifying the family member as providing support for fatigue management is needed. From a practice perspective, there is a need for intervention research on the management of fatigue. This study has demonstrated that the inclusion of family members is critical, and supports the conceptual model to guide nursing practice related to symptom management. 

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Acknowledgements

The authors wish to acknowledge the contribution of Karyn Colwell for her assistance in data collection and Colleen Clattenburg for the preparation and typing of this manuscript. This research was funded by Janssen-Ortho Inc. Fatigue Initiative.

Humber River Hospital Ad

A country of contrasts

By Wilma Falconer

Lebanon, a country of contrasts, embraced by the warmth of the Mediterranean to the west, and with snow-clad mountains, home to ancient cedar trees to the north. I remember the smell of cedar trees as we visited ancient Roman ruins in Baalbeck, a short trip from Beyrouth. The Roman temples were dedicated to Jupiter, Venus, and Bacchus. Adorning the temple of Bacchus, the Roman god of drinking and feasting, are found opium poppy flowers used to make morphine in ancient times, yet in this day and age cancer patients are often needlessly suffering in pain because of lack of adequate opioids. In Beyrouth, I was also struck by the new, mushrooming, multi-storey buildings standing side by side to the empty war-torn buildings filled only with machine gun holes. A country of contrasts indeed.

A sharing time

I had been graciously invited to share with doctors and nurses some of my experience in caring for advanced cancer patients. A two-day conference on palliative care and pain control had been organized in collaboration with Dr. Jan Stjernsward of the World Health Organization, Dr. Neil MacDonald of the Clinical Research Institute of Montreal, and the Lebanese Cancer Society. Mr. H. Tabbari, a private Palestinian sponsor, had generously supported the project financially. Doctors and nurses from the universities in Beyrouth, as well as a Palestinian delegation, were present. I felt most welcomed, especially at a time where there was growing political tension in the area. The enthusiasm and eagerness of the participants were evident from our discussions, and it felt most enriching to be surrounded by such dedicated and caring health care professionals from different religions and cultures, all coming together to learn how to improve the quality of life of advanced cancer patients in their country.

The objectives of the workshop were to present the components of a modern palliative care program and to identify the

current status of palliative care. Amongst important topics discussed was specific management of major symptoms such as pain, total pain, dyspnea, weight loss, and delirium. Indeed, pain and symptom management are major problem areas in palliative care that could be vastly improved upon in Lebanon. I also shared some of my experience in palliative home care nursing. One of our additional tasks was to help promote palliative care as an essential part of health care. The need to establish continuous opportunities for liaison and education was explored.

Several small group discussion sessions were held, enabling us to grasp the current status of palliative care in Lebanon. The participants shared freely the many difficulties they were facing.

The main problems seemed to be finances, follow-up or lack of it, poor home care, and completely inadequate pain control. We were told that of the 10,000 doctors in Lebanon, only 200 could prescribe morphine. Only long-acting morphine was available, with no short-acting morphine for breakthrough pain and initial dosage adjustment. The Fentanyl patch was available for the lucky few who could afford it. This brought to mind some of the luxuries we have here in Canada as we are able to rotate patients to different opioids when toxicities occur or when pain control is inadequate. We are indeed fortunate to have many tools at our disposal to treat difficult pain syndromes and neuropathic pain. Of utmost importance was to have a more readily available supply of opioids in the country, prescribed by knowledgeable and skilled physicians. Perhaps here a little help from Bacchus was needed! Some nurses expressed the lack of teamwork with physicians and the desire to improve this situation. They also stated their frustrations when the delicate task of 'truth-telling' to patients about their condition was not done by the physicians. This often left the nurses unable to truly establish a therapeutic relationship with the patients and family members.

The financial problems were evident; in a country recovering from war, palliative care was far down on the list of priorities. In fact, we were told that 90% of the

budget for cancer care was given to chemotherapeutic agents, 5% to prevention, and 5% to palliative care. The participants felt that one of their main tasks was to try to empower the families, to work with them, and to offer support and education. Many of the nurses present were educators and greatly aware of the monumental task before them. Home care was practically non-existent and families were naturally doing their best to care for their loved ones at home. Even with the lack of skilled home-visiting physicians and specialized palliative home care nurses here in Montreal, I felt somewhat guilty at presenting our ever-growing home care services and the many ways we are allowing people to die at home if they so choose.

Thoughts for the future

I felt very privileged to have been able to share some of my experience in caring for advanced cancer patients, whether in a palliative care unit, a hospice, or at home, with such an eager group of people. Their warmth and welcome, laced with the most delicious Lebanese food and wines grown in their fertile valleys, matched their interest and participation. It was clearly evident that they lacked resources, especially available opioids for pain management, but hopefully a process has been initiated with the government to improve this situation. A liaison network was set up and a plan was proposed for sponsoring both nurses and physicians to enable them to further their education and experience in palliative care here in Canada. Many e-mail addresses were exchanged.

I now realize how, here in Canada, the quality of life of advanced cancer patients is improving. Although still in its infancy, research in palliative care is beginning to grow at a steady pace, especially regarding pain control and symptom management. A greater awareness and financial support are blossoming. I left Lebanon with the feeling that a seed has been sown. I left with the feeling that no matter to which religion or culture we belong, or which country we abide in, there is a universal feeling of care and hope. The need for education and improvement of quality of life for terminal cancer patients and their loved ones is of the utmost importance world-wide. 🌱

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President's Message

A time to reflect and a time to evolve

This is my first opportunity to address my oncology nursing colleagues across the country as the CANO president. I am proud to be a part of this organization and to hold the office of president. On behalf of the organization, I will work to meet your expectations of the position as we implement the goals established in the recent strategic plan. I feel energized to work with the board, the chapters, and you, the members of CANO.

There is an old song, and forgive me for not remembering the words, but the song begins something like this, "To everything, turn, turn, turn, there is a purpose, and a time to every season under heaven." The song speaks to the need for reflection and understanding of the opportunities and challenges that life brings. The theme of this song was developed from Ecclesiastes, a book in the Bible. Ecclesiastes is a philosophical reflection on human life. In one of the chapters, the author begins to understand that there is a purpose for every event and everything that happens in our world. A time for planting, and a time for pulling up; a time for tearing down, and a time to build; a time for saving, and a time for throwing away, and a time for silence, and a time for talk. Not to belabour the point, but it seems appropriate to me, at the beginning of this presidency, to reflect on our accomplishments as we picture the future of our organization.

Many have contributed to CANO's successes over the years, from the founding

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President's Message

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members and their vision of the need for a Canadian oncology nursing organization, to those who worked intensely to achieve the distinction of oncology nursing as a specialty in Canada. Think back to conferences that you attended, to the fact that CANO has held conferences in most of the provinces across the country, from coast to coast, and most recently in Quebec. Think back to the Standards of Practice, the Standards of Chemotherapy Education and Patient Education, and how these influenced your practice; the hosting of the ISNCC conference in collaboration with CANO in Vancouver in 1994 and the opportunity to connect with oncology nurses from around the world; the awards for excellence in practice, education, research, and administration, and the many nurses who received those awards over the years (and the standing ovations, the tears and hugs from their colleagues to celebrate their successes). CANO members worked diligently to gain

special funding from industry to do the work of special initiatives in pain, fatigue, and, most recently, oncology nursing education. We have a website to communicate with our public and among ourselves, and it continues to be improved in its format and use. We have a great journal, CONJ, that is peer-reviewed and reflects the research, education, and practice domains of oncology nursing. CANO members have been invited to review materials for patient education, to participate in key national and international committees and organizations, such as Health Canada's Human Resource Planning, the NCIC, ISNCC, and the Canadian Strategy for Cancer Control, to name a brief few. This year marks the launch of the *Standards of Care, Roles in Oncology Nursing, and Competencies*, a project that has been underway for over two years. These are but a few of our accomplishments in the relatively short timespan of CANO as a national oncology nursing organization. No doubt many of you will identify many others of which we can be proud. All of these

endeavours are CANO's measures of success. These spur us on to the next level of directions and achievements, that is our strategic plan, mission, and vision.

By the time you read this message, the next phase of the strategic plan will be underway. Each CANO member received a letter from Carolyn Tayler outlining the process taken to reflect on the current structure of the board and organization, and the steps to review and revise the model to better serve the members across the country. Carolyn wrote in several of her messages in CONJ about the rationale for restructuring and the opportunities presented to us to evolve. My message to you in this journal is to take the time to consider the proposal and to exercise your vote to continue to build one of the best nursing organizations across the country. You have the power to influence the future of CANO and I urge you to use that power and to work with us to do the best for CANO. 🌱

Esther Green, CANO President

Message de la Présidente

Une période pour la réflexion et une autre pour l'évolution

Ceci représente la première opportunité qui me soit donnée, à titre de présidente de l'ACIO, de m'adresser à mes collègues infirmières en oncologie du Canada. Je suis fière de faire partie de cet organisme et d'y occuper les fonctions de présidente. Je vais faire tous les efforts possibles pour répondre à vos attentes relatives à la fonction que j'occupe tandis que nous mettons en œuvre les buts définis dans notre récent plan stratégique. Je me sens pleine d'énergie à l'idée de collaborer avec le Conseil national, avec les sections et avec vous, les membres de l'ACIO.

J'ai une vieille chanson en tête et vous me pardonneriez si je ne me souviens pas exactement des paroles, mais elle commence à peu près ainsi: "Chaque chose, tourne, tourne, a un but précis, et chaque saison a une période qui lui correspond". Cette chanson se penche sur le besoin que l'on a de réfléchir sur les opportunités et les défis que la vie nous réserve et de les comprendre. Le thème de la chanson est tiré d'Ecclésiaste, un des livres de la Bible. Le livre de l'Ecclésiaste est une réflexion philosophique sur la vie humaine. Dans un chapitre, l'auteur commence à saisir que

chaque événement, que chaque chose qui survient dans notre monde, sont là pour des raisons précises. Il y a une période durant laquelle on plante et une autre durant laquelle on récolte; une période pour démanteler et une autre pour bâtir; une période pour économiser et une autre pour dépenser sans limites; une période réservée au silence et une autre à la parole. Je ne veux pas insister sur ce point outre mesure, mais j'ai pensé qu'il serait approprié pour moi, à l'occasion de l'inauguration de ma présidence, de passer en revue nos réalisations alors que nous façonnons l'avenir de notre organisme.

De nombreuses infirmières ont contribué aux réussites de l'ACIO au fil des ans, depuis les membres fondateurs et la vision qu'ils avaient de la nécessité d'établir un organisme canadien pour les infirmières en oncologie en passant par les membres qui ont travaillé si fort en vue de faire reconnaître les soins infirmiers à titre de spécialité au Canada. Pensez aux conférences auxquelles vous avez assisté jusqu'à présent, au fait que l'ACIO a réussi à tenir sa conférence annuelle dans la plupart des provinces du pays, la plus récente au Québec. Remontez dans le temps et pensez aux Normes de la pratique, aux Normes de pratique et de formation des infirmières en matière d'administration de chimiothérapie anticancéreuse et aux Normes en matière d'éducation des patients en oncologie et du public: vous vous souvenez certainement de l'influence qu'elles ont

exercée sur notre pratique. Pensez à la conférence de l'ISNCC que cette dernière a tenue à Vancouver en 1994 en collaboration avec l'ACIO, et des liens qui pouvaient ainsi être noués avec des infirmières en oncologie du monde entier. Pensez aux prix d'excellence pour la pratique, l'enseignement, la recherche et l'administration ainsi qu'aux nombreuses infirmières qui se sont vu décerner ces prix au fil des ans (sans oublier les ovations, les larmes et les étreintes des collègues qui célèbrent ainsi ces succès). Les membres de l'ACIO ont travaillé d'arrache-pied afin d'obtenir des fonds spéciaux de l'industrie pharmaceutique à l'appui des travaux reliés aux Initiatives spéciales dans les domaines de la douleur et de la fatigue, et, plus récemment, dans celui de la formation des infirmières en oncologie. Nous possédons un site Web qui nous permet de communiquer avec notre public et entre nous; il continue d'ailleurs d'être amélioré sur le plan du format et de l'utilisation. Nous avons une superbe revue professionnelle, la Revue canadienne de soins infirmiers en oncologie ou CONJ selon son acronyme anglais, dont les articles sont soumis à la critique des pairs et qui s'intéresse aux domaines de la recherche, de la formation et de la pratique liés aux soins infirmiers en oncologie. On a demandé aux membres de l'ACIO de réviser du matériel d'enseignement aux patients et de rejoindre des comités et des organismes clés

d'envergure nationale et internationale tels que Planification des ressources humaines de Santé Canada, l'Institut national du cancer du Canada, l'ISNCC et la Stratégie canadienne de lutte contre le cancer, pour n'en citer que quelques-uns. Cette année marque le lancement des documents *Normes pour les soins, Rôles en soins infirmiers en oncologie et Compétences relatives aux rôles*, un projet qui dure déjà depuis deux ans. Ceci représente quelques-unes des réalisations accomplies par l'ACIO au cours de son existence, encore assez brève, d'organisme national des infirmières en oncologie. Il ne fait aucun doute que vous serez nombreuses à en identifier beaucoup d'autres qui sont pour

nous autant de sources de fierté. C'est à cette aune que nous mesurons la réussite de l'ACIO. Ces réalisations nous encouragent à passer au niveau suivant d'orientations et d'accomplissements, à savoir notre Plan stratégique, notre Mission et notre Vision.

Lorsque vous lirez ce message, l'étape suivante du plan stratégique aura déjà été lancée. Chaque membre de l'ACIO a reçu une lettre en provenance de Carolyn Tayler dressant les grandes lignes du processus adopté pour examiner la structure actuelle de notre organisme et de son conseil national et les étapes suivies pour étudier et réviser le modèle afin de mieux servir les membres de l'ensemble du pays. M^{me} Tayler a parlé, dans

plusieurs de ses messages parus dans la Revue, des raisons de la restructuration et des possibilités d'évolution qui se présentent à nous. Le message que je voudrais vous transmettre par le biais de la Revue est de bien vouloir prendre le temps d'examiner à fond notre proposition et d'exercer votre droit de vote afin de continuer l'édification d'un des meilleurs organismes infirmiers au Canada. Vous êtes à même d'influer sur l'avenir de l'ACIO et je vous incite à le faire et à œuvrer à nos côtés pour le plus grand bien de notre association.

Esther Green, Présidente, ACIO

Canadian Strategy for Cancer Control

Nursing's role in shaping cancer control for the future: The Canadian Strategy for Cancer Control

By Kim Chapman, RN, MSc(N),
CANO Secretary,
and Esther Green, RN, MSc(T),
CANO President 2001

Cancer rates are on the increase. More people are surviving cancer today than ever before in history. Even more people are learning how to live with or beyond cancer. The need to ensure that people receive quality cancer care in a timely way despite a compromised health care system is paramount. The economic implications of providing such care are driving an emerging crisis in cancer care. It is imperative that a strategy is devised to reduce and effectively deal with the cancer burden. No one

individual, group, or organization has the needed resources to address this situation alone.

History of the Canadian Strategy for Cancer Control

The Canadian Cancer Society (CCS), the National Cancer Institute of Canada (NCIC), the Canadian Association of Provincial Cancer Agencies (CAPCA), and Health Canada (HC) recognized the timeliness of initiating a process to develop a strategy for cancer control. In January of 1999, representatives from each organization formed a steering committee. The committee produced a plan for developing the strategy. Their goal was to create a comprehensive national strategy for cancer control, with input and support from the widest possible number of stakeholders involved in cancer care in Canada. They identified that cancer control, "aims to prevent cancer, cure cancer, and increase survival and quality of life for those who develop cancer, by converting the knowledge gained through research, surveillance and outcome evaluation into strategies and actions" (Luciani & Berman, 2000, p. 23). It can be accomplished through evidence-based strategies to prevent or reduce cancer and its impact, relevant laboratory and clinical research, appropriate surveillance to monitor and evaluate progress, and consensus building regarding the management and delivery of cancer care (Luciani & Berman).

The steering committee established two groups to move the strategy forward. Theme and topic working groups were created to address the areas of prevention, screening, diagnosis, treatment, supportive care/rehabilitation, palliative care, pediatric cancer, research, human resource planning, surveillance, genetics, and informatics/technology. Each group examined gaps and areas of priority, identified opportunities for improvement,

and made recommendations for their specific subject area. An integration group was formed to oversee and direct the work of the working groups. The integration group coordinated and reviewed the recommendations of the working groups with the aim of promoting integration across topic and theme areas. The integration group was comprised of representatives from the steering committee, the chair of each working group, and key stakeholders in cancer control (see Table One). While the steering committee spearheaded the initiative, it was the integration group's challenge to integrate recommendations presented by each working group in order to develop a national, coordinated, comprehensive cancer control strategy.

CANO's involvement in the Canadian Strategy for Cancer Control

CANO was invited to participate in this important cancer initiative as a member of the integration group. Kim Chapman represented CANO in this group. CANO's involvement at this level ensured that nursing's voice was heard in the development of all working reports and in the draft synthesis document. The invitation to participate at this level was also acknowledgement of nursing's essential role in cancer control. In addition, CANO members were invited to participate in the theme and topic working groups. The CANO executive and provincial directors actively recruited members to participate in the working groups. All of the names they received were then provided to the respective working group chairs. Working group chairs determined how they populated their working groups. Consequently, not all working groups were represented by a CANO nurse. Several CANO members officially represented CANO, while many

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Table One: Integration group members

- Canadian Association of Nurses in Oncology
- Association of Canadian Medical Colleges
- Canadian Association of Psychosocial Oncology
- Canadian Association of Radiation Oncology
- Canadian Coalition on Cancer Surveillance
- Canadian Oncology Society
- Canadian Public Health Association
- College of Family Physicians of Canada
- Community representatives
- Consumers' association of Canada
- Provincial/territorial representation
- Steering Committee
- Chairs of working groups

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other members participated, but as representatives for other groups or organizations (see Table Two).

At CANO's 2000 annual general meeting, Kim informed members about the reports generated by the working groups and the draft synthesis document that was produced, highlighting the feedback process members could use to further contribute to the evolution of the synthesis document. Information about CANO's participation in the strategy has also appeared in CONJ as a way to keep the membership informed.

Consensus building for change

The draft synthesis document was presented to the broadest possible range of cancer stakeholders at a consultation conference in Ottawa on February 1, 2, and 3, 2001. Two hundred and sixty-three people from across Canada, representing over 125 organizations, gathered in Ottawa in February to share their vision for cancer control. The three initiating organizations, CAPCA, CCS/NCIC, and HC, hosted the conference.

The purpose of the conference was to gather advice and consultation from the participants on the vision of the Canadian Strategy for Cancer Control, the overarching themes, and the next steps for implementation. A major outcome that was expected from the conference was the compilation of a synthesis report.

The strategy's vision guided discussion regarding cancer control in Canada:

The Canadian Strategy for Cancer Control will reduce the expected number of Canadians being diagnosed with cancer, reduce the severity of the illness and enhance the quality of life of those with cancer, and reduce the likelihood of dying from the disease, through consistent and effective application of existing knowledge, and through generation of new knowledge by research, across the cancer control spectrum.

If the strategy is achieved, then the following outcomes could be realized:

- Cancer-free lives, with effective prevention;
- Screening for common cancers is a part of wellness activities;
- Early detection of cancer;
- Access to high quality treatment and care throughout the cancer experience;
- Support and rehabilitation when needed;
- Through treatment and care, a dedicated guide to ensure that needs are heard and met;

- Closer-to-home cancer care and treatment, across Canada; and
- When cancer cannot be cured or held in remission, the assurance of good palliative care that focuses on pain and symptom control.

These outcomes drove the imperative to change, as all participants recognized that we have not achieved these goals within our provinces and communities. The participants were charged with the opportunity of devising ways to achieve this vision and outcomes through dialogue and sharing of ideas that would be incorporated into a final document for change.

There were nine themes of discussion, with opportunities for each participant to engage in discussion on at least two themes throughout the two full days of the meeting:

1. Structure
2. Re-balancing focus: The whole context from prevention through to palliation and supportive care
3. Seamless, integrated care: Appropriate models and staff
4. Standards: Measures by which care can be assessed

5. Accountability and reporting: Accountability for resource utilization and results achieved
6. Education: For health professionals, people with cancer, their families, and the public
7. Human resources: Short- and long-term planning to ensure that care is available
8. Research: Utilization, priority-setting, funding, and human resource development of researchers
9. Advocacy: Building collaborative relationships for action.

There was much debate and discussion among the participants within each of the theme groups. Each group consisted of members representing health professionals, advocacy groups, researchers, administrators, educators, and clinicians. Several oncology nurses participated in the groups: Kim Chapman, Karima Velji, Margaret Fitch, Karen Tamlyn, Esther Green, Mary Ellen Gurnham, Marlene Mercer, and Marie-France Vachon. Previous work by CANO nurses contributed to the discussion document, such as the human resources theme where Jocelyn Bennett was

Table Two: CANO members involved in theme and topic working groups

Theme working groups	CANO members who were selected by working group chairs to participate in the working groups	Names of CANO members submitted to the chairs of the working groups
Research		Dauna Crooks
Surveillance		Pam Baker
Human resource planning	Jocelyn Bennett	Jocelyn Bennett
Information and technology		Pam Baker
Genetics		Pam Baker
Topic working groups		
Prevention		Kathy Fitzgerald
Screening		Kathy Fitzgerald
Diagnosis	Catherine Root, Margaret Fitch	Kathy Fitzgerald, Catherine Root, Cindy Sinnott, Sheryl McDiarmid, Judy Jodouin-Coutu
Treatment	Sheryl McDiarmid	Pam Baker
Supportive care/rehabilitation	Margaret Fitch (Dawn Stacey provided input)	Angela Bunting
Palliative care	Rhea Arcand, Christine Power	Ann Syme, Christine Power, Laurie O'Brien, Rose Steele
Pediatric Care	Linda Bergeron, Bernice Dawe	Pam Baker

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a member, and the theme of re-balancing the focus where Margaret Fitch contributed her expertise on the development of a supportive care model. As a member of the integration group, Kim participated in reviewing each working group report and providing feedback. She also assisted with integrating the reports to produce the draft synthesis document; a document which reflected high level, strategic recommendations. Kim ensured that recommendations were ones that CANO could and would support.

The following is a synopsis of the major issues developed for each theme:

Structure. Establishment of a Canadian Council for Cancer Control (CCCC) that would coordinate the development, implementation, and monitoring of a comprehensive strategy for cancer control. Notions of responsibility, broad spectrum representation, including advocacy and patient support groups, authority and clear mandate, and span of control were included in this recommendation.

Re-balancing focus. Three areas were identified for priority:

- Establishment of a national/provincial/territorial primary prevention system to address population-based risk factors;
- Palliative care fully incorporated into the cancer control system; and
- Access to supportive care and rehabilitation.

Seamless, integrated care. The notion of navigation across the continuum of care was the first priority in this theme. There were strong recommendations for the improvement of communication across the continuum and the recognition of the need for human resource planning, with palliative care resources identified as a priority.

Standards. The need to define, implement, and evaluate national standards across the cancer control continuum. To do so requires the development of a permanent oversight group with broad representation, along with the establishment of surveillance, evaluation, and reporting processes. The final recommendation in this area was the development of standards on human resources to drive decision-making in the future.

Accountability and reporting. Several issues were included in this theme: The notion of a framework for CSCC with national accountability mechanisms, periodic reporting, and an external review process.

Education. Recommendations were developed in four areas:

- Establishment of an education working group with four target focus areas: patients, public, health professional, and other provider education;
- Development of a national chronic disease prevention system;
- Endorsement and implementation of the Carstairs report on palliative care; and

- Development of patients' bill of rights and responsibilities.

Human Resources. A three-pronged approach was recommended:

- Funding a national media campaign to recruit and retain health care professionals;
- Funding a national comprehensive strategy for human resources to address the 70% increase in cases by the year 2015; and
- Funding a national, targeted program to address the inequities in human resources across the country.

Research. A strategic alliance was formed among the NCIC, CIHR, and CAPCA to bring the research community together to define research priorities, create a strategic plan, and develop a business case.

Advocacy. The theme of advocacy was promoted through a mission statement to act together to achieve sustained, long-term funding for a universal cancer control strategy that is the best in the world.

The steering committee submitted the final synthesis document to the Deputy Ministers of Health in June 2001.

CANO's future role in cancer control

Being part of the strategy, especially the integration group, provided CANO with some incredible opportunities. CANO's presence allowed us to increase awareness and educate members of the cancer community about nursing's significant contribution to cancer care across varied settings and in all phases of the cancer experience. Nurses have been, and will continue to be, leaders in the delivery of innovative cancer care. Through varied discussions, we were able to share our vision for oncology nursing, ensuring strategy recommendations help us realize our vision. Most importantly, we were there to speak for nursing. We were able to guide and shape not only cancer control, but how cancer nursing will look in a coordinated, comprehensive cancer control system. We know that future delivery of cancer care will create new opportunities for nurses in areas never before thought possible. Our challenge for the future will be to ensure that we are active participants in the implementation of the strategy. We need to continue to identify ways to ensure that nursing's voice is heard. Participation in the strategy is but only one way.

Reference

Luciani, S. & Berman, N. (2000). Status report: Canadian Strategy for Cancer Control. *Chronic Diseases in Canada*, 21, 23-25.

SHORT-TERM CLINICAL ONCOLOGY TRAINING PROGRAM FOR HEALTH CARE PROFESSIONALS IN CANADA

The Canadian Cancer Society (National) offers an award to provide financial assistance for health care professionals to attend short continuing education programs (not more than 100 hours total course content) for the purpose of augmenting their knowledge and skills in the care of patients with cancer.

This award is offered twice a year, each spring (April) and fall (October). The actual dollar amount of these awards may vary based on each applicant's proposed program as well as the number and quality of other applications received in each application cycle.

Complete terms and conditions of these awards and application forms are available on our website: www.cancer.ca. Click on "What We Do" followed by "Fellowships and Bursaries".

If you have questions or would like more information about this award please contact: Sarah Kettel, Canadian Cancer Society (National)

10 Alcorn Avenue, Suite 200, Toronto, ON M4V 3B1

Tel: 416-934-5673; Fax: 416-961-4189

E-mail: skettel@cancer.ca

Oncology Nursing Society Report

Report From ONS 2001: The Oncology Nursing Society 26th Annual Congress, May 17-20, 2001, San Diego, California

By Kim Chapman, RN, MSc(N)
CANO Secretary

Over 5,400 oncology nurses from across the United States and several other countries gathered together in San Diego, California for the 26th Congress of the Oncology Nursing Society (ONS) between May 17 and 20, 2001. San Diego, a city as rich and varied in history as ONS, was a wonderful background for "Pursuing Excellence in Challenging Times," the theme of the congress. I was privileged to not only attend the conference, but to be there as a representative of CANO. Following are some highlights of the congress.

During the four conference days, I had the opportunity to attend several plenary sessions and a wide variety of topic-specific instructional sessions. Of interest was a schedule change the conference planning committee made this year. The committee adjusted the schedule so that sessions on the last day were a repeat of previous presentations. Participants who had to leave early on the last day did not miss out on sessions. People participating on the last day had the opportunity to select additional sessions during the week.

The annual "Hot Topics" session reviewed the latest in cancer care information on radiation therapy, biotherapy, chemotherapy, and legislative issues. The session provided current information about breaking news in cancer. Information was collected within a maximum of 30 days before the congress, ensuring that presenters had their fingers on the pulse of the latest in cancer care information.

Every year, the congress offers a special symposium. This year the symposium introduced the concept of "distress" in patients with cancer. Various presenters (Jimmie C. Holland, MD, Ruth McCorkle, PhD, RN, FAAN, Nancy W. Fauzy, RN, DNSc, and Eleanor B. Saltzer, PhD, RN, FAAN) delivered the symposium entitled, "Psychosocial Standards of Care Regarding Distress." Speakers focused on practical strategies to help nurses adopt and implement the standards in their practice setting. Participants engaged in a discussion with the presenters following the formal presentations. Discussion expanded on the concept of distress, described a technique for initial screening assessment for patient distress, and identified three referral

resources for managing patient distress.

Lillian Nail, PhD, RN, FAAN, presented the 20th annual Mara Mogensen Flaherty Memorial Lecture entitled "I'm Coping as Fast as I Can: Psychosocial Adjustment to Cancer and Cancer Treatment." Dr. Nail is the May F. Rawlinson Endowed Professor and a senior scientist at Oregon Health Sciences University School of Nursing. She is also a member of the Oregon Cancer Center.

Dr. Nail provided a rich synthesis of empirical and clinical experience in supporting individuals and families coping with cancer. She described practical suggestions for interacting with patients and their families, sensitized attendees to coping and psychosocial issues that arise during the cancer experience, and underscored the differences between individual and care provider perspectives. She also addressed dying, fear of recurrence, hope, the need for information, trust, and the importance of excellent symptom management.

Her presentation style was most memorable. She had a wonderful ability to describe her topic in a humorous style, drawing specific examples from her research, clinical experience, and personal experience as a cancer survivor. I caught myself laughing on more than one occasion throughout her presentation. I would welcome the opportunity to hear her speak again. You can view Dr. Nail's slide presentation at no cost on ONS' web site, www.ons.org.

Rebecca Hawkins, MSN, ANP, AOCN delivered the ONS clinical lecture. Hawkins guided participants through the pathophysiology of metastatic disease. She reviewed the methods of metastatic spread and factors that promote it such as angiogenesis, cell attachment, and so on. Her presentation really helped to enhance my knowledge and understanding of the assessment, intervention, and evaluation of metastatic disease.

A highlight of the conference for me was the opportunity to attend a press release session regarding the U.S. nursing shortage delivered by Pearl Moore, RN, MN, FAAN, Chief Executive Officer of the ONS. I had the opportunity to discuss the nursing shortage with Moore prior to the press release. During the press release, Moore addressed the need for legislative changes at the national level to support private initiatives, ways to reshape nursing education, and ways to improve the quality of work life for nurses. She referred to the 18-point position laid out by ONS on May 17, 2001 that called for the public and private sectors to address and resolve the growing U.S. nursing shortage. The position statement appears in volume 28, number 6 of

Oncology Nursing Forum (2001).

Moore emphasized that we must ensure that nurses are present to care for the growing, aging population who will be diagnosed with cancer. She identified that, "Cancer care is a complex, multifaceted, chronic disease and people with cancer require specialty nursing interventions at every step of the cancer experience. Patients with cancer are best served by nurses specialized in oncology care, especially RNs who are certified in this specialty. The nursing shortage will impede the provision of quality cancer care through a lack of nurses trained in the specialty of oncology."

Another highlight of the conference for me was the opportunity to meet Dr. Victoria Champion, world-renowned for her research in breast screening. Dr. Champion had served as an expert consultant to a project team that I had participated in over the past two years. It was very fitting that she was the recipient of the ONS Distinguished Researcher Award because of her many significant research contributions that have supported and advanced oncology nursing practice.

The ONS Congress provided an excellent opportunity to network with colleagues. As I circulated throughout the convention centre, visited the exhibitors, attended the various sessions, and wandered through the poster presentations, I talked with nurses from throughout the U.S. and other countries about varied oncology nursing practices. I discovered more about ONS' organizational structure, particularly relevant because CANO has been strategizing about its own organizational structure. I was amazed to learn that there are 31 SIGS in ONS, and the number of chapters has grown steadily over the years. In fact, ONS welcomed another chapter into its organization at this conference. I was intrigued to discover more about ONS' virtual congress, a feature that many nurses highly value. ONS first introduced its virtual congress to much success a year ago following its 25th annual congress. Select instructional and plenary sessions can be viewed free on their website. Members really enjoy the ability to earn education credits through the virtual congress for up to two years after each congress. What a wonderful feature! Maybe CANO can offer something similar in future!

I left the congress with a strong sense of pride in the work and vision of CANO because I realized that, as a much younger organization, CANO has made great strides in such a short time! Would I go back to another ONS congress? Definitely!! The experience was wonderful. In fact, it is an opportunity that every oncology nurse should experience at least once.

Congratulations to the following Canadian nurses who obtained certification in the speciality of oncology within the past year

CON(C) (2001)

Anjali Bala, Alberta
 Angela Bunting, Alberta
 Alicja Derkacz, Alberta
 Gary Frank, Alberta
 Larissa Podilsky, Alberta
 Lisa Shirt, Alberta
 Sally Turco, Alberta
 Linda Andrews, British Columbia
 Linda Bruce, British Columbia
 Sue Christensen, British Columbia
 Elizabeth Cooper, British Columbia
 Ladonna Fehr, British Columbia
 Maria Gul, British Columbia
 Nancy Hartt, British Columbia
 Louise Kay, British Columbia
 Florence Kronstal, British Columbia
 Gayle Magrath, British Columbia
 Betty Murray, British Columbia
 Allison Palmer, British Columbia
 Dixie-Lee Rosher, British Columbia
 Shelley Speck, British Columbia
 Lily Wong, British Columbia
 Julia Barley, Manitoba
 Jenny Billey, Manitoba
 Ginette Carriere, Manitoba
 Dawn Christenson, Manitoba
 Evelyn De Grave, Manitoba
 Barbara Hues, Manitoba
 Pamela Johnston, Manitoba
 Marilyn Kilpatrick, Manitoba
 Joanne Loughery, Manitoba
 Holly Mulvihill, Manitoba
 Kathy Ramesar, Manitoba
 Donna Romaniuk, Manitoba
 Mary Stones, Manitoba
 Penny Williams, Manitoba
 Shauna Boitson, New Brunswick
 Hayley Kyle, New Brunswick
 Caroline Merritt, New Brunswick
 Kimberly Ross, New Brunswick
 Kathryn Wilmot, New Brunswick
 Anne Carter-Hayes, Newfoundland
 Pamela Druken, Newfoundland
 Yvonne Gulliver, Newfoundland
 Janice Manuel, Newfoundland
 Charlene Walsh, Newfoundland
 Heather Dixon, Nova Scotia
 Lynda Eastham, Nova Scotia
 Jo-Ann Edwards, Nova Scotia
 Nancy Farmer, Nova Scotia
 Patricia Harley, Nova Scotia
 Jo-Ann Martin, Nova Scotia

Lorraine Abra, Ontario
 Valarie Ali, Ontario
 Jacki Armstrong, Ontario
 Sharon Aucoin, Ontario
 Barbara Ballantyne, Ontario
 Sarah Barry, Ontario
 Franzis Barton, Ontario
 Linda Bater, Ontario
 Carole Beals, Ontario
 Anita Cadeau, Ontario
 Nancy Candido-Gregorio, Ontario
 Angela Candon, Ontario
 Carolyn Carson, Ontario
 Grace Chan, Ontario
 Joanne Constantineau, Ontario
 Johnson Dartey, Ontario
 Eileen Davis, Ontario
 Pauline Davis, Ontario
 Kristy Dillon, Ontario
 Stella Dizes, Ontario
 Nancy Dorscht, Ontario
 Jacinthe Forget, Ontario
 Magda Foster, Ontario
 Shelley Gallipeau, Ontario
 Suzanne Gardner, Ontario
 Danielle George-Chayka, Ontario
 Laura Giannantonio, Ontario
 Deborah Giffen, Ontario
 Leesa Goode, Ontario
 Carrie Gratton-Muir, Ontario
 Michele Harris, Ontario
 Donna Head, Ontario
 Debra Hendel, Ontario
 Cynthia Hill, Ontario
 Gwen Jackson, Ontario
 Linda Johnston, Ontario
 Barbara Kaitila, Ontario
 Margaret Kelderman, Ontario
 Deborah Labelle, Ontario
 Jean Lake, Ontario
 Susan Lee, Ontario
 Cora Lewis, Ontario
 Iwona Lorenc, Ontario
 Mary-Ellen Love, Ontario
 Cheri Lumsden, Ontario
 Donna Maguire, Ontario
 Lisa Maracle, Ontario
 Sharron Maskevich, Ontario
 Margaret McCormack, Ontario
 Cynthia McLennan, Ontario
 Lynda Messmer, Ontario
 Katherine Mitchinson, Ontario
 Maureen Mohr, Ontario
 R Morgan, Ontario

Tracey Mullen, Ontario
 C Bonnie Peacock, Ontario
 Elizabeth Pelton, Ontario
 Heather Perkins, Ontario
 Tara Peters, Ontario
 Lisa Pike-Young, Ontario
 Natalie Puim, Ontario
 Pamela Ross, Ontario
 Monica Splinter, Ontario
 Dawn Stacey, Ontario
 Valsa Thomas, Ontario
 Carole Veenema, Ontario
 Millie Wagenaar, Ontario
 Maryon Walter, Ontario
 Sheryl White, Ontario
 Deborah Wilkinson, Ontario
 Andrea Willett, Ontario
 Carol Wlodek, Ontario
 Lorna Zubrickas, Ontario
 Maryse Bilodeau, Québec
 Nancy Biron, Québec
 Marie-Thérèse Caron, Québec
 Giselle Charrette, Québec
 Caroline Gendron, Québec
 Nancy Hutchison, Québec
 Sandie Stéphanie Larouche, Québec
 Tiziana Vadacchino, Québec
 Susan Bollinger, Saskatchewan
 Sheri Briggs, Saskatchewan
 Mary Dagnone, Saskatchewan
 Cheryl Whiting, Saskatchewan
 Patricia Yuzik, Saskatchewan
TOTAL: 138

OCN® - September 2000

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 Shawn V. Bourne,
 Heather A. Chilton,
 Sasha E. Deane,
 Margo Ferguson,
 Clare V. Johnston,
 Diane L. Johnston,
 Hee-Jin B. Kim,
 Donaldal L. MacDonald,
 Teresa Parker

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Michael Dyson

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Brenda M. Peters-Watral

CPON - September 2000

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Mark Your Calendar!

Prenez Date!

To take advantage of this free service, submissions must be brief and received two months prior to the event. Include the following: **Event, Date, Location, Contact Person, Fee.**

Pour pouvoir utiliser ce service d'annonces gratuites, vous devez envoyer un bref texte, deux mois avant la date de l'événement en question. Veuillez inclure les détails suivants: Événement, Date, Lieu, Personne(s) à Contacter, Frais d'inscription.

Publication dates Submission dates

May 1	March 1
August 1	June 1
November 1	September 1
February 1	December 1

Dates de publication

le 1^{er} mai
le 1^{er} août
le 1^{er} novembre
le 1^{er} février

Dates de réception

le 1^{er} mars
le 1^{er} juin
le 1^{er} septembre
le 1^{er} décembre

- November 14-16, 2001 **The Odyssey: IV Therapy in the New Millennium.** CINA 26th Annual Convention. International Plaza Hotel and Conference Centre, 655 Dixon Rd, Toronto, ON.
Contact: CINA, 18 Wynford Drive, Suite 516, North York, ON M3C 3S2,
(416) 445-4516, fax (416) 445-4513,
cinacsot@idirect.com or website <http://web.idirect.com/~csotcina>
- November 16-17, 2001 **Pain and Symptom Management.** The Old Mill, Toronto, ON.
Contact: Continuing Education, Faculty of Medicine, University of Toronto,
150 College Street, Room 121, Toronto, ON M5S 3E2, (416) 978-2719, fax (416) 971-2200.
- January 25, 2002 **The Canadian Cancer Society Essay Prize for Oncology or Cancer Control (Nursing).**
N.B. Applicants must be in an undergraduate nursing program in Canada.
Contact: Monica Dixon, CCS (National),
10 Alcorn Avenue, Suite 200, Toronto, ON M4V 3B1.
(416) 934-5673, fax (416) 961-4189, mdixon@cancer.ca
- April 12, 2002 **Canadian Cancer Society (National) Clinical Award.** Contact: Monica Dixon,
CSS (National), 10 Alcorn Avenue, Suite 200, Toronto, ON M4V 3B1.
(416) 934-5673, fax (416) 961-4189, mdixon@cancer.ca
- April 18-21, 2002 **Oncology Nursing Society 27th Annual Congress.** Washington, DC.
Contact: Pearl Moore, ONS, Pittsburgh, PA.,
(412) 921-7373, fax (412) 921-6565, member@ons.org
- May 13-15, 2002 **Grief Across the Life Span.** 20th King's College Conference on Death and Bereavement.
London ON. Contact: Dr. John Morgan, King's College Centre for
Education About Death and Bereavement,
266 Epworth Avenue, London, ON N6A 2M3,
fax (519) 432-0200, jmorgan@uwo.ca
- Aug. 28 - Sept. 1, 2002 **Making a Difference.**
Twelfth Annual International Conference on Cancer Nursing (ISNCC).
London, UK. Contact: Emap Healthcare Events, Greater London House,
Hampstead Road, London NW1 7EJ, UK, conference.healthcare@emap.com
- Sept. 22-25, 2002 **The Spirit of Caring: At the Crossroads of Oncology Nursing.**
L'esprit de compassion: Les soins infirmiers oncologiques à un carrefour.
14th annual national CANO Conference. Fort Garry Hotel, Winnipeg, MB.
Contact: CANO Office, 329 March Road, Box 11, Suite 232, Kanata, Ontario, K2K 2E1,
(613) 270-0711, fax (613) 599-7027, canoacio@igs.net

NOTE: Please direct all calendar entries to the Editor-in-Chief, Rose Steele, RN, PhD, Room 404, School of Nursing, Joseph E. Atkinson Faculty of Liberal and Professional Studies, York University, 4700 Keele Street, Toronto, ON M3J 1P3, telephone (416) 736-2100, ext. 40556, fax (416) 736-5714, e-mail: rose.steele@sympatico.ca

We will highlight media reviews (books, videos, films, tapes, pamphlets, etc.) and new products. All reviews must be accompanied by your name, position and agency.

Nous publierons les critiques de médias (livres, vidéos, films, cassettes, brochures, etc.) et celles de produits nouveaux. Chaque critique doit être accompagnée de votre nom, de votre poste et de votre lieu de travail.

Materials on Review Critique des nouvelautés

Self-Healing: Powerful Techniques

Author: Ranjie N. Singh, PhD.
Published in 1998 by Health
Psychology Associates Inc.,
London, ON, Canada. Hardcover,
256 pages. ISBN # 1-896826-00-8.
Cost: US \$24.95 Hardcover;
US \$12.95 Tape.

Reviewed by Lynda G. Balneaves

As an alternative/complementary therapy for cancer and a variety of other diseases, melatonin has received considerable attention from the general public and the health research community. The book, **Self-Healing: Powerful Techniques**, provides information on how simple, 10- to 30-minute mind-body techniques can stimulate the pineal gland and naturally increase production of melatonin in the body. The mind-body techniques described were tested during the author's PhD research at the University of Western Ontario. Directed towards both lay and health professional audiences, the book is divided into two parts; the first section is written for the general public and the second section provides greater technical and theoretical information for scientists and health professionals. An instructional, meditative tape is also available to provide additional assistance to individuals in performing the mind-body techniques.

The first section focuses on the importance of melatonin in overall health and how mind-body techniques influence melatonin production and improve physical, emotional, and spiritual well-being. The first chapter provides a review of research on the pineal gland and melatonin and the potential link to the neuro-immuno-endocrine-cellular-bioelectric systems within the body. Chapters two to four describe the breathing techniques, visualization exercises, and meditative

intonations that comprise the mind-body techniques. Chapters five to seven provide a theoretical perspective of meditative intonation, drawing from such fields as psychoneuroimmunology, quantum vibrational medicine, Vedic medicine, and mysticism. Chapters eight and nine review the role of diet, thought, and therapeutic touch on pineal gland activity and provide practical recommendations. The final chapter of this section concludes with the suggestion that a new "quantum-spiritual" paradigm is needed in medicine that supports mind-body interventions. A list of important terms is also provided, along with a summary of other publications and workshops available from the publishers.

The second section reviews the theoretical and methodological elements of Singh's research. A brief description of the study's methodology and findings is provided. Numerous figures, tables, and illustrations are used throughout this section to illustrate the neurophysiological pathways through which meditative intonations are hypothesized to influence psychophysiology, consciousness, energy fields, and spirituality.

Considerable effort has been made to simplify very complex ideas and theories into language and illustrations that are easily understood by the general public. Contributing to the accessibility of this book, key points are summarized at the beginning of each chapter and a larger font size is used throughout the text. Bolding and italics are used to highlight central concepts and ideas, which, at times, are overused and quite distracting to the reader.

While the author makes an earnest attempt to bridge the gap between eastern and western healing paradigms and to provide a scientific foundation for mind-body techniques, several aspects of this book should concern readers. Foremost, it was apparent by the provocative language used (e.g., "a stunning medical breakthrough"), the

use of patient testimonials, and the inclusion of a list of materials and workshops available from the publisher that the author was not unbiased in the promotion and study of mind-body techniques. Further, insufficient information was given to accurately assess the validity and reliability of Dr. Singh's research. The small sample size (12 health participants; three participants with cancer), the ambiguity regarding data collection, and the lack of a control group raise concerns regarding the applicability and generalizability of the study findings. In particular, the suggestion that this technique can "prevent or reverse" serious conditions, such as cancer, is unsubstantiated by the research. The over-reliance on secondary literature sources and the inconsistent referencing of medical claims raise additional skepticism regarding the scientific credibility of this work.

Overall, this book highlights an innovative area of mind-body medicine that holds potential for future research and practice. The mind-body techniques described may be of some interest to health care practitioners and the informed consumer familiar with meditation techniques and comfortable with a holistic model of health care. In addition, this book may act as a resource for nurses caring for clients who are interested in, or are using, melatonin as a complement to their medical care. With regard to oncology nursing, this book is not particularly relevant and may even raise unrealistic expectations in individuals with cancer regarding the possible outcomes of mind-body interventions. A healthy dose of skepticism is warranted when reading this book. ♦

Lynda G. Balneaves, RN, PhD(c), is a doctoral candidate in the School of Nursing at the University of British Columbia.

Food for Thought

By Dawn Daley

Reflection note from author

So often we never know what to say to a person battling with cancer or to a family member whose loved one is desperately ill. "I'm sorry" seems so insignificant and does nothing to help the person fight their lengthy battle...or does it? I tried to put myself in the shoes of those who are faced with such ordeals in attempts to gain a greater understanding of what I could do to help those who may need me. Of course, I could never realize the full implications of such a traumatic event. However, I hope my attempts were not in vain and my thoughts can somewhat reflect those of someone with cancer.

How would I feel...

How should a person treat me
If cancer some day should strike?
A million thoughts run through my head,
Just what would it be like?

No pity do I want from you,
Doesn't matter if it's bad.
A useless emotion; of no good
That will only make you sad.

Keep me in your thoughts and prayers,
But on my illness do not dwell.
It will only serve to make you ill
And will not make me well.

What I would like the most is this;
Support me! Be my friend.
Just be there, so I'm not alone,
A listening ear please lend.

And after dreaded treatments,
A party for me throw.
Buy hats and scarves, I'll need them most;
They'll help, more than you know.

And if it's God's will, the disease should win,
Don't cry for days on end.
Rejoice for what we've had and shared,
And thank God for dear old friends.

Assuming emotions

She was just 58 years old when I worked with her. It was during the summer of 2000 when I was employed in a student position on an orthopedic floor. The woman was admitted to the hospital with an orthopedic problem. While on our floor, she underwent various tests and discovered that she had terminal cancer. To make matters worse, her husband had recently died of cancer and her son was currently battling the disease.

I went into her room one day just after mealtime to see how she had made out with her lunch. She had barely touched her tray, claiming she had no appetite. I gave her a sympathetic look, and lowering my voice I said, "Oh, you're not really hungry, are you?" Almost instantly she piped up and questioned, "Why does everyone come in here hanging their heads at me?" Taken aback, I did not know how to react or even what to say. I apologized, claiming my sympathies were directed toward her because she had no desire to eat. But it was only after I left her room that I realized the impact her statement left with me and how it would be reflected in my future nursing interactions.

I reflected on what had happened and shared the impact it had on me with my co-workers. I knew before entering her room that day that I would not be as cheery or bubbly as I so often am, because she had just received devastating news. I "assumed" she would be very down and possibly even depressed. I "assumed" she would not want someone coming into her room acting as if the world was a wonderful place. I "assumed" wrong. I learned an important lesson while working with this patient; the importance of meeting clients midway in dealing with their emotions. In other words, the importance of meeting clients where they are at.

As nurses, we can never assume emotions, even in the most predictable situations. We have to enter our patients' rooms with a clear mind and work with the emotion at hand. Each person is an individual with different thought processes and lives. What affects one person a certain way may differ entirely for another. Some patients may want our sympathies, allowing sadness and the expression of emotions without attempts in "cheering them up." In contrast, others may wish to have their caregivers make light of the situation, be very uplifting, thus enabling the patient to get his/her mind off the disease process for a while.

My patient was the latter of these two types of patients and, after learning this, I

changed my behaviour entirely. There were no more sympathetic looks and sad faces when I entered the room. Instead, there were cheery "hellos" between us, we talked about her family support systems, and expressed concerns were addressed. This was the way things worked between us right up until the time she was discharged. I was shaken to learn that this lady has since passed away after only a very short time, but I will remember what she taught me forever. As nurses, we are in a position to assess patients' emotions and help facilitate both the illness and wellness processes. How we perceive the situation at hand makes no difference; it is what our patients display that is of utmost importance. To listen, to learn, and to care are the duties we have that are valued by our patients; they are the duties of a skilled nurse.

Cancer: I am the dreaded killer

I am the dreaded killer.
The whisper of my name,
Brings fear and so much sorrow,
No other one can claim.

I attack at will, no mercy!
No class escapes my wrath.
I enter any body;
No one exempts my path.

You can be a little baby,
Or a senior - black or white.
I enter any body;
For your life you'll have to fight.

I make my victims suffer,
And no medicine will surely cure,
The damage I've inflicted,
A toll I'll take for sure.

My pain is so far reaching,
Victims' loved ones feel such stress.
I take a happy family,
And make their lives a mess.

If I go undetected,
I'll spread 'til it's too late.
Another victim I have conquered,
And death will be her fate.

My only fear is research,
Some day it just might bring,
An end to my reign of terror;
It will be the only thing.

Dawn Daley is a nursing student at the University of New Brunswick in Fredericton, NB.

This section is reserved for you to share practice tips with colleagues. It's an ideal spot for a novice writer to get initiated.

Voilà une section qui vous est réservée pour que vous partagiez des "tuyaux" de pratique avec vos collègues. C'est l'endroit idéal pour se découvrir des talents d'écrivain.

CONJ MEMO

From: The Members

To: The Members

Where to start... finding cancer information

By Dawn Stacey and Christine Penn

How often have you heard a patient say, "I just can't find any information"? With so much written about cancer today, it is hard to believe that patients can't find anything. Not only do patients want to find information, but they are also asking other

questions such as, "Where should I go to find information? How will I know if it is good? What information is most appropriate for my situation?"

Concise, easily understood information helps patients a) cope with their diagnosis by reducing anxiety and enhancing self-efficacy; b) participate in treatment-related

decisions; and c) learn self-care strategies to manage side effects of treatment (Davison & Degner, 1997; Ream & Richardson, 1996; Rees & Bath, 2001; Stacey, Jacobsen, & O'Connor, 1999; Treacy & Mayer, 2000). Information can be provided through various formats that include written materials (e.g. pamphlets, books, websites, or decision aids), videos, one-to-one teaching, group education sessions, support groups, and telephone hotlines. For many years at the Ottawa Regional Cancer Centre, patients were provided with information on chemotherapy and/or radiation therapy that included tips on managing side effects of treatment. However, we had been less diligent about providing patients with information about their type of cancer.

In 1998, to help patients find information, the "Where to Start? Sources of Information on ..." sheets were created. The purpose of these sheets is to identify various sources where patients could **begin** to access information on their own. Each sheet provides informational resources that are classified as basic information, more detailed information, telephone hotlines, books, websites, decision aids, and support groups (see Table One). The preference is to provide Canadian resources that are free-of-charge or available through a local library. Support groups within the region are also profiled. To date, a total of 14 sheets have been developed for specific cancers (e.g. breast, colon, lung, prostate, lymphoma, brain, skin and melanoma, gynecologic, mouth and throat), healthy lifestyle practices (e.g. exercise, nutrition), complementary therapies, and common cancer-related symptoms such as fatigue and lymphedema. Each sheet is available in English and French; English on one side and French on the other, with the French sheets promoting resources available in French when possible (see Table Two). These sheets are updated yearly or more often by a library technician and a nurse coordinator for patient education. New topics are developed when the need arises. The "Where to Start" sheets can also be easily adapted to other regions and can be used as a template for other medical conditions.

Table One: Where to start? Sources of information on breast cancer

Basic information	Facts on Breast Cancer booklet: A 21-page booklet providing information about breast cancer, its diagnosis and treatment. Produced by the Canadian Cancer Society. Available in the information area at the Cancer Centre or local Canadian Cancer Society offices. No charge.
More* information	Breast Cancer and You magazine: A 38-page magazine providing detailed information about breast cancer, its diagnosis and treatment. Produced by Amgen Canada. 2 nd edition, 1999. Available at the Cancer Centre at the Ninon Bourque Patient Resource Library. No charge.
Telephone hotlines	Cancer Information Service: 1-888-939-3333 Willow: Ontario Breast Cancer Support Centre 1-888-778-3100
Books*	1. Dr. Susan Love's Breast Book , 3 rd ed., Perseus Publishing, 2000. 2. The Intelligent Patient Guide to Breast Cancer by Ivo Olivotto, Intelligent Patient Guides, Vancouver 1998.
Decision aids*	Making Decisions About the Removal of My Breast Cancer: What do I Prefer? A decision aid (booklet & cassette tape) to help you decide, along with your surgeon, which type of surgical treatment you personally prefer for your breast cancer. For more information or to obtain a copy, call Cancer Information Service 1-888-939-3333.
Support groups	Breast Cancer Action: Provides one-on-one peer support, community education and advocacy, and information referral. Call 736-5921 for more information. Reach to Recovery: Provides emotional and practical information to women undergoing treatment for breast cancer. Call 723-1744 for more information.
Websites	Canadian Breast Cancer Network: http://www.cbcn.ca National Cancer Institute information on the specific cancers and treatment.: http://www.cancernet.nci.nih.gov

*Available at the Ninon Bourque Patient Resource Library at the General Division of the Ottawa Regional Cancer Centre. For more information call (613) 737-7700 ext. 6980
Last updated 06/01.

continued on page 213...

continued from page 211...

To improve patient accessibility, these sheets are available in the patient resource library, at awareness week displays, on the website, and in clinical areas for health care professionals to hand out to patients. Several cancer support groups and other facilities that provide services to cancer patients in the region also make them available.

To obtain copies of the "Where to Start" sheets, visit the cancer centre website at www.orcc.on.ca and follow the signs to "For Patients & Families" then "About Cancer" or send your request via e-mail to bott@orcc.on.ca

Dawn Stacey RN, MScN, CON(C) is a Research Associate at the Ottawa Health Research Institute, University of Ottawa.

Christine Penn is a Library Technician at the Beattie Library, Ottawa Regional Cancer Centre.

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Table Two: Par où commencer?

Sources d'information sur le cancer du sein

Renseignements de base

Brochure sur le cancer du sein

Brochure de 21 pages qui offre de l'information à propos du cancer du sein, son diagnostic et son traitement. Produite par la Société canadienne du cancer. Disponible au kiosque d'information du Centre de cancérologie ou aux bureaux de la Société canadienne du cancer. Offerte gratuitement.

Autres* renseignements

Revue Vous et le cancer du sein

Revue de 38 pages qui présente des renseignements détaillés à propos du cancer du sein et des méthodes de diagnostic et de traitement. Produite par Amgen Canada. Disponible à la bibliothèque de documentation pour patients Ninon Bourque au Centre de cancérologie. Offerte gratuitement.

Services d'aide téléphonique

Service d'information sur le cancer : 1 (888) 939-3333
Willow : Centre de soutien pour le cancer du sein en Ontario 1 (888) 778-3100

Livres*

1. Le cancer du sein et autres maladies du sein.

June Engel ; traduit par Anne-Catherine Hattan.

- Laval, QC : Guy SaintJean, 1997.

2. Traiter le cancer du sein.

Jean-Claude Paquet.

- Cap-rouge, QC : Les Éditions Vul Med, 1996

Trousse de décision*

Veillez voir au verso pour les renseignements sur la trousse de décision disponible en anglais.

Groupes d'entraide

Breast Cancer Action/Sensibilisation au cancer du sein

Fournit des services d'aide individuelle, de formation communautaire, de représentation et d'orientation. Pour plus de renseignements, composez le 736-5921.

Toujours femme

Fournit un soutien affectif et des renseignements pratiques aux femmes qui subissent un traitement en raison d'un cancer du sein. Pour plus de renseignements, composez le 723-1744.

Sites Web

Société canadienne du cancer :

<http://www.cancer.ca/indexf.htm>

La Fondation québécoise du cancer :

<http://www.fqc.qc.ca>

Réseau canadien du cancer du sein:

<http://www.cbcn.ca>

**Disponibles à la bibliothèque de documentation pour patients Ninon Bourque de la Division Générale du Centre régional de cancérologie d'Ottawa. Pour plus de renseignements, composez le (613) 737-7700, poste 6980. Dernière mise à jour : 06/01*

Make-A-Wish

The Make-A-Wish Foundation is the largest and most respected wish granting organization in the world. With chapters in 22 countries, Make-A-Wish has granted over 80,000 wishes worldwide to children between the ages of three and 18 years old diagnosed with a life-threatening illness. A wish offers a child who is sick - laughter, strength, and hope during a very difficult time.

For more information, please visit www.makeawish.ca or call 1-888-822-WISH.

Is there some program or someone you would like to see profiled because of the contribution made to oncology nursing in Canada? We welcome suggestions.

Y a-t-il un programme ou une personne que vous aimeriez voir figurer dans notre section "Profil" pour sa contribution aux soins infirmiers en oncologie du Canada? Vos suggestions sont les bienvenues.

In Profile

A regional approach to palliative pain and symptom management

By Nancy Keat

Background

In December 1992, the Ontario Ministry of Health announced funding for four initiatives designed to enhance the care of those with life-threatening or terminal illness.

The four initiatives are:

1. Education of multidisciplinary service providers. This initiative provides funding for introductory [Level I] and advanced [Level II] educational programs.
2. Education of family physicians. Funding for this initiative is directed through Ontario medical schools.
3. Support and maintain hospice volunteer visiting programs. This initiative provides funding to existing volunteer programs to enhance services.
4. Establish pain and symptom management teams in all areas of Ontario. The broad mandate of this initiative is to work towards ensuring that people with life-threatening or terminal illness and their families have access to service providers who have expertise in the management of pain and other distressful symptoms. Funding for this is channelled through the provincial long-term care offices. Coordinators were hired to establish these teams throughout the province.

Development of the Southwestern Ontario Palliative Pain and Symptom Management Program

The southwestern Ontario region includes the 10 counties of Essex, Kent, Lambton, Elgin, Huron, Middlesex, Oxford, Perth, Grey, and Bruce. A southwest region palliative care committee was formed. This committee included the coordinators and other representation from each of the 10 counties. The goals of this committee were to identify and address issues of a regional nature and to collaborate on the development of the initiatives in the region.

Initially, each coordinator's role included pain and symptom management consultation as well as education [initiatives 1, 2, and 4]. Consultation was primarily via the telephone. Service providers and consumers in the community, long-term care facilities, and hospitals were able to contact the coordinator for information concerning available palliative care services, pain and symptom management, and general palliative care issues.

An education coordinator was hired to work with the county coordinators to plan and develop education programs in the 10 counties. Funded education opportunities included a 30-hour introductory Level I course, a five-day institute for advanced level learning [Level II], a local refresher

day, and a mentoring program. Providing physician education in the Level II program has combined initiatives one and two. This was done to promote the team approach to palliative care. The mentoring program was a 30-hour course, held in individual long-term care facilities, that offered a combination of 15 hours of teaching and 15 hours of mentoring to a core group of staff members.

While all of the coordinators had an overall role in developing and improving existing palliative care services, there was variation in how the coordinator fulfilled the roles of consultant and educator. This occurred for a number of reasons. For example, one coordinator was full-time and others were part-time. The full-time coordinator had responsibility for five counties, whereas the part-time coordinators had one or two counties. Some areas involved large geographic distances, while other areas were smaller.

Impetus for change

The need to review roles and responsibilities concerning the initiatives in the southwest region arose from a number of factors. The education coordinator, who had primary responsibility for planning the educational opportunities, was leaving the area. Her responsibilities needed to be redistributed. As well, structural and funding revisions in the region encouraged equity of responsibilities among the coordinators.

A number of factors pointed to the need for the coordinators to be more accessible to the service providers. The telephone consultation service, providing access to palliative care resources and pain and symptom expertise, is very beneficial in many cases. However, in some cases, and depending on the experience and knowledge of the caller and the complexity of the case, telephone consultation may be of limited benefit. When coordinators had provided "site consultations," there were great benefits in terms of networking, teaching, assessment, and problem-solving.

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The educational opportunities help raise awareness and increase knowledge, but in terms of developing and maintaining expertise, it is vital to have experience with large numbers of patients with varied situations. This is not the case for service providers in many smaller communities. As well, it has been evident that education has not always been successful in modifying or changing attitudes which act as barriers to excellent pain and symptom management. Also, the mentoring programs were effective while the mentor was involved, but over time, without ongoing support of the mentor, new practices and knowledge were not sustained. These factors suggest that teaching opportunities alone are not sufficient to improve pain and symptom management practices. Ongoing involvement of the coordinators, acting in the role of developmental/mentor, may be more effective in the longer term.

A pilot project was conducted in Perth County to determine if a pain and symptom management consultant who was more available to service providers in hospitals, long-term care facilities, and the community would be more effective in developing positive relationships with providers and improving access to pain and symptom management. The findings of the pilot supported the role of a mentor in an ongoing resource/developmental role. The number of referrals to the coordinator for pain and symptom management increased and the coordinator was able to facilitate a number of collaborative projects and partnerships in all care settings. Service providers reported that the comfort of those for whom they provide care was improved through the involvement of the coordinator. All of these factors together pointed to the need to review and revise the roles and responsibilities of the coordinators.

Current program

The new role - palliative pain and symptom management/education consultant - integrates some of the responsibilities of the former education coordinator role with the previous education responsibilities of the coordinator and involves an expanded role for pain and symptom management consultation. The southwest region has been restructured to include 12 areas - the 10 counties plus London and Windsor (considered as separate areas because of larger populations). There are five full-time consultants who each have responsibility for two areas and two part-

time consultants who each have one area.

The role is still developmental in nature and intent. The consultants continue to offer services to consumers and service providers in the community, long-term care facilities, and hospitals, such as telephone consultation regarding pain and symptom management, educational opportunities, available palliative care services and resources, and palliative care issues in general. In addition, they are now able to offer some site consultations which are very effective as teaching opportunities and in building relationships between the consultants and the agency and facility staff. However, in the pain and symptom management role, the consultants are not able to offer emergency or 24-hour seven-days-a-week coverage. In hospitals, long-term care facilities, and in the community, the consultants can model assessments and discuss symptom management strategies with the service providers. During these visits, the consultants learn more about the environment and learning needs of the individual agencies/facilities that helps in planning of future education projects. As well, the consultants are available to assist agencies and facilities in developing their palliative care services, committees, or teams.

Each of the 12 areas is funded for three Level I programs and one refresher day each year. The consultants ensure that the programs are offered in their areas, although their degree of involvement may vary from one area to the next. In some areas, local palliative care committees organize the programs and the consultant may participate in some way such as a planner or a presenter; in other areas, the consultant may have a more integral role in organizing the programs. The Level I program is an introductory level and presents the 'art' of palliative care. Level I targets all service providers and volunteers. The refresher days are meant to be a follow-up of the five-day institutes and present information at an advanced level, but anyone may attend. Because they are one-day events and held locally, they are usually well-attended and the networking that occurs is valuable.

The five-day institutes are residential programs that are offered twice a year. The consultants all participate in the planning and organization of the institutes and each of the consultants presents at least one session. The information is at an advanced level and the target group is professional service providers, including physicians. Because much of the material is not relevant to volunteers and health care aides who do

not attend the institutes, planning is underway to develop an advanced program for this group. Participants have the opportunity to hear presentations by regional experts and to network with the consultants and with others from work settings similar to theirs.

The mentoring programs will still be offered in the long-term care facilities, but the consultant will act as the mentor. Another difference is that after the 30 hours of teaching and mentoring has been completed, the consultant will be able to continue in the mentoring role. How this occurs will depend on the facility, but some regular contact will be planned.

The changes that have been made to the program are in response to the lessons we have learned so far. It is hoped that the increased availability and involvement of the consultants will result in improved palliative care services and pain and symptom management in the region.

Provincially, the programs that have been developed to address these initiatives differ in response to the diverse needs of the areas they serve. In 1994, the pain and symptom coordinators across the province formed a coordinators' network. This network allows sharing of ideas and strategies and identifies opportunities to address common issues. This sharing also facilitates linkage of service providers and consumers with palliative care services across the province. The network members are also members of the Ontario Palliative Care Association and the Canadian Palliative Care Association. This involvement allows the coordinators to influence both provincial and national developments in palliative care.

A sub-committee of the provincial coordinators' network is completing a process evaluation of initiative #4 - the pain and symptom management initiative. First, a logic model was developed based on the initiative. A survey was formulated and completed by the coordinators. Currently, the results are being processed. Because the provincial programs are so diverse, the goal is not only to describe the activities of the various programs, but also to identify activities that are common to all programs. Once these common activities are listed, the next step will be to plan an outcome evaluation of initiative #4. ♦

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