
CANADIAN ONCOLOGY NURSING JOURNAL

REVUE CANADIENNE DE SOINS INFIRMIERS EN ONCOLOGIE

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Table of Contents/Table des matières

Guest editorial/Éditorial d'invitée spéciale	1
Articles	
2000 Helene Hudson Memorial Lecture - Decisional role in seriously ill hospitalized patients near the end of life: The patient's and provider's perspectives..... <i>Joan Tranmer and D. Heyland</i>	8
Conférence à la mémoire de Helene Hudson 2000 - Le rôle décisionnel chez les patients hospitalisés gravement malades en fin de vie: la perspective du patient et celle du soignant..... <i>Joan Tranmer et D. Heyland</i>	14
The utilization and efficiency of the informal caregivers' coping strategies	21
<i>Gemma Aucoin-Gallant</i>	
L'utilisation et l'efficacité des stratégies de «coping» de la soignante naturelle	24
<i>Gemma Aucoin-Gallant</i>	
Linking nursing pain assessment, decision-making and documentation	28
<i>Carolyn Tayler and Barbara McLeod</i>	
Communiqué	
President's message/Message de la présidente.....	33
CONEP Report/Rapport du CONEP	34
Strategic planning.....	35
Planification stratégique	36
CANO Awards	36
Prix décernés	38
CANO Conference 2000/Conférence de l'ACIO de 2000	40
CANO Conference 2000 - presenters	41
CANO Conference 2001/Conférence de l'ACIO de 2001	44
CANO/Pharmacia Awards of Excellence winners.....	45
Features/Rubriques	
Reflections on Research	6
Mark Your Calendar/Prenez date	51
Materials on Review/Critique des nouveautés	52
For Enquiring Minds	52
In Profile	53
Guidelines for Authors.....	58

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REVUE CANADIENNE DE SOINS INFIRMIERS EN ONCOLOGIE

Guest editorial

President's speech 2000

Submitted by Carolyn Tayler,
CANO President

Honoured guests, CANO members, and conference participants, as president I am proud to welcome you this morning to Victoria and the 12th annual conference of the Canadian Association of Nurses in Oncology.

My speech has been reverently placed in this CANO folder. Remember when we used to supply these? It was called our first annual conference, "Bridging the Nation", and was held in 1988 in Vancouver. I wonder how many of you were at that conference in 1988 and are here today? I see many familiar faces, and I welcome many of you who may be attending your first CANO conference. The conference returns to this, my adopted province of BC, 12 years later and has the honour of being the first conference of the new century and I feel an excitement and optimism about what we can accomplish together as oncology nurses in Canada.

Our newly developed vision states that CANO will be a dynamic organization, recognized locally, provincially, nationally, and internationally as the voice for Canadian oncology nurses. We will be recognized as the voice for oncology nursing in Canada. In the strategic planning process which we just recently completed, we learned that a vision is defined by William Bryson in his 1995 book, **Strategic planning in public and non-profit organizations**, as an idealised future state, something that an organization aspires to be at some future time. It represents a dream which in itself may not be possible, but for which an organization constantly strives, such that its reach is always slightly beyond its grasp.

This issue of voice was raised at the conference of the Canadian Nurses Association held in Vancouver this last June and which I attended on behalf of CANO. We heard from Suzanne Gordon, a feminist journalist who, along with Bernice Buresh, wrote a book published by the CNA in 2000, **From silence to voice - What nurses know and must communicate to the public**. Patricia Benner, in the foreword to the book, describes it as a manifesto, calling on nurses to apply their courage and develop the skills to speak out forcefully, indeed to "find their voices."

In my address to you today, I want to challenge you to think about being the voice of oncology nursing - what would it mean to

you personally and to us collectively as oncology nurses if we truly were the one voice of oncology nursing in Canada? And most importantly, how will we move towards this vision of being recognized locally, provincially, nationally, and internationally? Our vision statement goes on to describe us as using the energy, the expertise, and the participation of our members to advance the delivery of cancer services in Canada. We want to be leaders in the areas of administration, education, practice, and research. What do we need to be doing now, so that in five years time we will be closer to this vision?

What would it look and sound like to be the voice of oncology nursing? We might envision that CANO would define standards for oncology nursing practice, that we could describe and show exemplars of oncology nurses working in a variety of roles as nurses in the health care system. CANO would define the competencies required by nurses to meet these roles, as well as how these competencies are linked to achieving the standards we have set. The standards would sit in the offices of every administrator, educator, and nursing office where cancer care is provided. Universities and colleges would look to CANO to set curriculum standards in undergraduate, graduate, and PhD programs. Health care agencies would design continuing education strategies around the guidelines.

Politicians would call us up if they were making policy about cancer care, developing budgets for care delivery, or doing human resources planning. Other professional groups in Canada such as physicians, social workers, radiation therapists, and others would want to collaborate with us on projects, issues, and conferences. CANO nurses would sit on editorial boards for journals; CANO nurses would be represented on all major cancer organizations such as the National Cancer Institute of Canada, the Canadian Oncology Society, the Canadian Cancer Society, and the newly-formed Canadian Association of Provincial Cancer Agencies. And not only would we be invited to sit at these tables of influence, but, as Suzanne writes in her book, we would "be full-fledged, vocal and assertive decision makers who would be listened to and respected for our views." CANO membership would increase to more substantially represent the number of nurses actually caring for cancer patients in this country and we would double the number of nurses who would be certified and influenced by our speciality. Patients and families would be educated to understand that they require care from nurses who have received the appropriate speciality education and are qualified to provide care in all settings - home care, acute care, and ambulatory care.

I am sure you can think of many examples of what it would mean at your work, if your voice on behalf of nursing were to be heard? So, let's ask ourselves honestly, do we have a voice now? How loud is it? Is it a whisper, a whimper, a whine? Is it growing in strength? Is it sounding angry or frustrated, apathetic, or just plain exhausted? Or can we infect ourselves with some enthusiasm and energy?

Leah Curtin, the prolific editor of **Nursing Management**, asked "Is it possible that our preoccupation with the problems, obstacles, and frustrations of practice has blotted out our achievements, advances and successes?" The theme of this conference is "*Weaving the tapestry - Our future is now,*" and I believe it is essential that we move past these doubts and frustrations to shape our future. And looking to that future, we need to review our past accomplishments. What has CANO achieved that would lead us to believe in our vision? CANO was established in 1985, which is only 15 short years ago, and was the first national association to support Canadian nurses in promoting oncology nursing. We have many achievements with which to be proud: all provinces are represented, we have a national office and management structure, we hold an annual conference which is a major source of funds that support our organization, as our fees cover only a small percentage of our activities. We have a peer-reviewed journal with an excellent reputation. We provide educational scholarships and awards of excellence and we are collaborating with our industry partners in major initiatives around pain, fatigue, and oncology education. We have CANO members on the boards or committees of a number of national organizations: the National Cancer Institute of Canada, Canadian Oncology Society, Canadian Breast Cancer Initiative, Cancer Advocacy Coalition. On the international scene, we are very proud to have Dr. Marg Fitch as president-elect of the International Society of Nurses in Cancer Care.

In 1997, we established national oncology certification through the Canadian Nurses Association. I have had nurses tell me that they do not see why it is necessary for them to belong to CANO since CNA is the organization that runs the certification program. They are not aware that it was CANO members who put in a tremendous effort to ensure this was an option available to oncology nurses in Canada and that the exam was based on the practices of Canadian nurses and the CANO standards. Today, 830 nurses are certified in oncology. As a member of the Canadian Oncology Society, we have launched a website which offers us a new way of communicating with our members and we are just learning how to use it as an effective tool.

These are some of our many accomplishments over a relatively short period of time, but what is yet to be done? How will we strengthen our voices as oncology nurses in Canada? These are the questions which we put to our members, our board, and external stakeholders in order for us to develop our strategic plan. We came up with five key objectives: 1) the need to redevelop our organizational infrastructure and establish financial security; 2) to strengthen our leadership role related to health care policies and increase our public profile; 3) to broaden the diversity of our membership and increase the numbers of members; 4) to develop an ability to respond to patient advocacy issues; and 5) to develop and implement a national education strategy which would support and evaluate the role development, knowledge, and expertise in adult and paediatric oncology nursing in Canada. A very challenging list and one which I believe will bring the vision that we have of becoming the recognized voice of oncology nursing within our grasp and indeed a reality. But it is going to require real leadership - and not just from the executive and board, but from each one of you in your provincial chapters and at your workplaces. You need to be the eyes, ears, hands, and voices of CANO. We will all need to let go of how we have done it in the past; I see an urgent need to examine the infrastructure as it relates to how we do our business and how we work as a board.

I am an individual blessed with a certain abundance of energy, but I can tell you after being in the position of president for a year that it is difficult to do well "off the side of your desk" when we all know how high our desks are piled these days. Is it time for us to move to a paid, professional support position, such as an executive director? We need to challenge our old concepts of how provinces are represented on the board. Can we afford a board member from every province? It is the old Canadian dilemma of equalization and regionalization. Should we look at a western, central, and eastern region? Do we need to add other voices besides that of nursing to our board in order to bring in other areas of expertise such as finance, marketing, and law? These are some of the many questions which we are going to be asking ourselves in an open and thoughtful way as we move into this next phase of the strategic planning process. Nothing should be sacred; all questions need to be raised and all possibilities looked at, by as wide a constituency as possible, and I hope each of you will ask yourself what your contribution could be to the process.

I believe we are facing a fork in the road that will see us choosing between one path of expansion, heightened visibility, and

energy, reaching out to embrace change or one of defence of the status quo and the inevitable shrinking that I believe will occur if we fail to move forward. No doubt we will be able to come up with a lot of excuses as to why we should stay the same. In these difficult times within the health care system, it is easy to be pessimistic and certainly to feel exhausted. But remember what is at stake: improving care for cancer patients and the quality of our professional work life. Never in my career has the timing been better; we have the ear of the public and the government. But our voices need to be loud, to be firm, and to be united! I believe all of the actions and goals we have aspired to in our strategic planning exercise, which we will discuss at our AGM on Tuesday, are indeed possible with the commitment, energy, and talent that we have in oncology nursing in Canada. We need to regain a sense of optimism that we can carve out our destiny. Think back in your own careers about how much you have changed and how much the world of health care has changed.

I did not think that standing up here today would be a part of what I was called to do as a nurse, but I have come to realize that to effect widespread change one has to make efforts which are outside of the everyday practice domain. CANO has given me a place where I believe that can happen. I have been and continue to be inspired by those who have worked beside me on the executive, board, and all the committees. The amount of work over the past year has been extraordinary; our membership is up to almost 1,000 despite the reality that numbers of nurses in Canada are actually decreasing; at this conference we have an impressive syllabus and an excellent turnout; our financial situation has improved; the CONEP group is presenting its new draft standards of care; the pain initiative is presenting its first educational module; we have renewed the fatigue initiative; and we have a comprehensive strategic plan for the future. Most importantly, we have had the talent and I think the commitment to see ourselves through a difficult past year and have come out with renewed strength.

I want to say a special thank you to Rose Steele and Heather Watson, co-chairs of this conference, and to the planning committee here in Victoria and the BC Oncology Nurses Group. We have a wonderful few days ahead of us, thanks to their efforts, and never once did they ever fail to show an absolute confidence in themselves and in this organization. I was inspired by their hard work and sustained enthusiasm.

I want to conclude today by referring to my speech last year in Halifax. I have had so

many requests to repeat this story by Kathleen Mooney which first appeared in the Oncology Nursing Society newsletter (**ONS News**, 11(10), October, 1996) that I realized it was a message that spoke to many nurses. Last year, I asked nurses to follow the lead of our fine feathered friends the geese who, when they are flying south, do so in a V formation:

"So that each goose creates an updraft of wind for the goose flying behind it. This drafting effect allows the flock to fly more than 70% farther than a goose flying alone. A goose that strays from the formation is quickly reminded of the assistance and power created by the uplift of the others when confronted with the wind resistance of flying alone. Geese have discovered the value of a strong community and the need for a single, well-focused direction. We need to learn from the geese and work to strengthen our community. Fly in unified formation, support one another with a positive updraft, and speak with a united voice about nursing's contributions to quality cancer care. The geese also teach us about leadership and mentorship. If the lead goose gets tired or disoriented, it will fall back into formation and another goose will take the lead position for awhile. As they do, we need to recognize our interdependence and share leadership responsibilities. Often, we expect our leaders to take care of our concerns while we are only silent partners. But to be successful, we must be willing to share the difficult work and take our turn. Finally, geese can teach us something about support and encouragement. Geese honk from behind as they fly in formation. They do this to encourage those in front to maintain their speed. Unfortunately, nurses have the tendency to be critical of others when they are working in a group facing difficult issues. We need to remember that geese honk encouragement and support, not criticism, for they know that encouragement is the most effective way to move forward."

Now I can tell you that I heard a lot of honking this past year.... It came in many forms; from the lovely pewter goose that Nancy pinned on me before I even left Halifax last year, to the e-mailed words of encouragement and appreciation for something I had written or said, calls from numerous nurses whom I had never met who wanted to pass on an idea or ask a question about CANO, calls from executive and board members and nurses asking how I was doing, could they help? This has really kept me going and if I did not tell you before, I want to express my thanks now for all the support.

So this year, as I sat on the beach at our family cottage in late August, just as the sun was setting beautifully behind the mountains, we could hear a flock of geese coming before

we could actually see them. My husband commented that there were my CANO friends encouraging me on ... as the first flock flew by, my family, who now knows many of you by name, affectionately pointed out various members!! We not only were treated to one flock flying by, but they came in, wave after wave, small and large, fast and slow, spread out and close together, some had many loud honkers and some very few, and lo... I had a new vision... I saw that, like those waves of geese, CANO has many diverse groups: younger and older nurses, managers and researchers, clinicians and educators, union and non-union, national executives and provincial executives, diploma and degree nurses, specialized nurses and general nurses, nurses who work in home care and in hospitals. As Rose and Heather so eloquently noted in their invitation to this conference, "each nurse brings to the tapestry a colour, each brings their part to be woven in." And so, our task is the same as those flocks of geese. To fly in formation, keep heading south, honk with encouragement at each other, honk so all know we are coming, and let our honks or our voices be so loud that they hear us long after we have left. So during this conference, let us continue to honk, let us raise our voices in celebration of what we have accomplished, search out new voices to join us and speak with one voice about the needs of cancer patients and their families. ✨

Éditorial d'invitée spéciale

Discours de la présidente - Conférence 2000

Présenté par Carolyn Tayler,
présidente de l'ACIO

Chers invités de marque, membres de l'ACIO et congressistes: j'ai le plaisir ce matin, en tant que présidente, de vous souhaiter la bienvenue à Victoria et à la 12^e conférence annuelle de l'Association canadienne des infirmières en oncologie.

Vous remarquerez que mon discours a été respectueusement placé dans cette pochette de l'ACIO, que nous avons l'habitude de distribuer, jadis, aux congressistes. Notre première conférence annuelle qui s'intitulait "Rapprocher la nation toute entière" a eu lieu à Vancouver en 1988. Je me demande combien d'entre vous ont assisté à cette conférence de 1988? Je vois de nombreux visages familiers et j'accueille également de nombreuses

infirmières qui assistent peut-être aujourd'hui à leur toute première conférence de l'ACIO. Ainsi, quelque douze ans plus tard, la conférence annuelle visite de nouveau la Colombie-Britannique, ma province d'adoption, et elle se distingue des autres en ce qu'elle est la première du nouveau siècle; c'est avec excitation et optimisme que j'entrevois les réalisations que mèneront à bien les infirmières en oncologie du Canada.

Selon la vision de l'ACIO que le Conseil national vient à peine de mettre au point, notre association sera un organisme dynamique, reconnu à l'échelle locale, provinciale, nationale et internationale comme étant la voix des infirmières en oncologie du Canada. On reconnaîtra en nous la voix des soins infirmiers en oncologie de ce pays. Lors de l'élaboration de notre plan stratégique que nous avons récemment achevée, nous avons appris que la vision, selon la définition de William Bryson dans son ouvrage **Strategic planning in public and non-profit organizations** publié en 1995, est l'état futur idéalisé de l'entité, ce que l'organisme souhaite devenir à un point donné du futur. La vision représente un rêve, dont la concrétisation complète est peut-être impossible, mais que l'organisme s'efforce d'atteindre, mais elle est telle qu'elle reste toujours légèrement hors d'atteinte.

Cette question de "voix" a été soulevée lors du congrès de l'Association des infirmières et infirmiers du Canada (AIIC) qui a eu lieu à Vancouver en juin dernier et auquel j'ai assisté au nom de l'ACIO. Nous y avons entendu Suzanne Gordon, une journaliste de tendance féministe, qui avait rédigé en compagnie de Bernice Buresh un livre publié par l'AIIC en 2000: **From silence to voice - What nurses know and must communicate to the public**. Dans l'avant-propos de ce livre, Patricia Benner avance que ce dernier est un vrai manifeste et incite les infirmières à prendre leur courage à deux mains et à développer les compétences qui leur permettront de faire connaître leur opinion et donc, de «trouver leur voix».

Dans mon discours d'aujourd'hui, je me propose de vous lancer le défi de vous faire la voix des soins infirmiers en oncologie – de réfléchir à ce que cela signifierait pour vous, personnellement et collectivement en tant qu'infirmières en oncologie si nous devenions, au Canada, l'unique et véritable voix des soins infirmiers en oncologie. Et plus important encore, comment pouvons-nous réaliser notre vision de reconnaissance locale, provinciale, nationale et internationale? Notre énoncé de vision décrit comment notre organisme tirera profit de l'énergie, de l'expertise et des contributions de ses membres pour faire progresser, au

Canada, les services offerts aux personnes atteintes de cancer. Nous voulons jouer un rôle de leader dans le domaine de l'administration, de la formation, de la pratique et de la recherche. Que devrions-nous faire dès aujourd'hui afin que d'ici cinq ans, nous nous soyons rapprochées de cette vision?

De quoi aura l'air la voix des soins infirmiers en oncologie? Nous pourrions nous imaginer que l'ACIO sera appelée à définir les normes de la pratique des soins infirmiers en oncologie, que nous décrirons et mettrons en vedette des infirmières modèles en oncologie occupant divers rôles au sein du système de soins de santé. L'ACIO définirait les compétences exigées des infirmières en fonction de ces rôles ainsi que les liens que les compétences entretiennent avec les normes établies par l'Association. Les normes occuperaient une place de choix sur le bureau des administrateurs, éducateurs et prestataires de soins infirmiers partout où l'on soigne des patients atteints de cancer. Les universités et collèges se tourneraient vers l'ACIO lors de l'établissement des normes des programmes d'études de premier, deuxième et troisième cycles. Les établissements de soins élaboreraient des stratégies en matière de formation continue en se fondant sur nos lignes directrices.

Les personnalités du monde politique nous consulteraient lors de la mise au point de politiques de santé relatives au cancer, de l'élaboration de budgets de prestation de soins ou de la planification des ressources humaines. Divers groupes de professionnels de la santé du Canada tels que médecins, travailleurs sociaux, radiothérapeutes et bien d'autres encore voudraient collaborer avec nous sur certains projets, questions ou conférences. Des infirmières de l'ACIO siègeraient à des conseils de rédaction de revues professionnelles; d'autres représenteraient notre association auprès de tous les grands organismes de lutte contre le cancer comme l'Institut national du cancer du Canada, la Société d'oncologie du Canada, la Société canadienne du cancer et la toute nouvelle Association canadienne des organismes provinciaux de lutte contre le cancer. Non seulement on nous inviterait à nous asseoir autour de ces tables d'influence, mais encore, comme le dit Suzanne Gordon dans son livre, nous serions des «décideurs de plein droit qui affirmeraient sans ambages leurs opinions, et que les gens écouteront et respecteraient». L'ACIO attirerait un nombre toujours croissant de membres qui refléteraient plus fidèlement les diverses catégories d'infirmières prodiguant de fait des soins aux patients atteints de cancer dans notre pays, et nous doublerions le nombre d'infirmières certifiées et

influencées par notre spécialité. Les patients et les proches comprendraient, à force d'éducation, qu'ils doivent être soignés par des infirmières qui ont reçu une formation adéquate dans la spécialité et qui possèdent les antécédents nécessaires pour prodiguer des soins dans quelque milieu que ce soit – soins à domicile, soins actifs, soins ambulatoires.

Je suis certaine que de nombreux exemples vous viennent à l'esprit de ce que votre lieu de travail deviendrait si votre voix, la voix des soins infirmiers, était entendue? Demandons-nous alors sincèrement si nous avons une voix à l'heure actuelle? Quels en sont le volume et la nature? S'agit-il d'un murmure, d'un gémissement ou d'une plainte? Va-t-elle en s'amplifiant? Se caractérise-t-elle par la colère ou la frustration; par son apathie ou sa grande fatigue? Ou bien serions-nous capables de lui insuffler de l'enthousiasme et de l'énergie?

Leah Curtin, la rédactrice prolifique de la revue *Nursing Management* y posait la question suivante: «Est-il possible que la préoccupation que nous avons montrée pour les problèmes, obstacles et frustrations associés à la pratique ait effacé nos réalisations, nos progrès et nos réussites?» Cette année, la conférence a pour thème *«Tisser la nouvelle tapisserie des soins infirmiers en oncologie: notre avenir se décide maintenant!»* et je pense qu'il est essentiel que nous dépassions ces doutes et ces frustrations si nous voulons être à même de construire notre avenir. Et pour façonner ce dernier, il nous faut passer en revue nos accomplissements. Quelles réalisations de l'ACIO pourraient nous amener à croire en notre vision? Notre organisme fondé en 1985 – il n'y a pas plus de quinze ans – fut la première association d'envergure nationale à appuyer les infirmières canadiennes en matière de promotion des soins infirmiers en oncologie. Et nous pouvons être fières du chemin parcouru depuis: les provinces y sont toutes représentées, nous avons un bureau national et une structure de gestion, nous organisons une conférence annuelle qui nous aide à recueillir les fonds nécessaires au soutien de notre organisme puisque les cotisations ne couvrent qu'un infime pourcentage de nos activités. Nous nous sommes dotées d'une revue professionnelle - dont les articles sont soumis à l'évaluation des pairs - qui jouit d'une excellente réputation. Nous offrons des subventions de formation et des prix d'excellence et coopérons avec nos partenaires du secteur industriel à d'importantes initiatives axées sur la douleur, la fatigue associée au cancer et la formation en soins infirmiers en oncologie. Des membres de l'ACIO siègent au conseil d'administration ou dans les comités de

divers organismes d'envergure nationale: Institut national du cancer du Canada, Société d'oncologie du Canada, Initiative canadienne sur le cancer du sein, Coalition action-cancer Canada. Sur la scène internationale, un de nos membres, le Dr Marg Fitch est présidente désignée de l'ISNCC (Société internationale des infirmières en cancérologie).

En 1997, nous avons démarré un programme de certification nationale en oncologie par le truchement de l'AICC. Malheureusement, des infirmières m'ont déjà dit qu'elles ne voyaient pas le besoin de se joindre à l'ACIO puisque le programme de certification est sous la responsabilité de l'AICC. Elles ignorent le fait que ce sont des membres de l'ACIO qui ont fait des mains et des pieds pour que les infirmières en oncologie du Canada puissent se faire certifier dans leur propre pays, et que l'examen est basé sur la pratique des infirmières canadiennes et sur les normes de l'ACIO. Aujourd'hui, 830 infirmières ont mérité la certification en oncologie. À titre de membre de la Société d'oncologie du Canada, notre organisme a inauguré son site Web qui nous fournit un nouveau moyen de communiquer avec nos membres et nous commençons à en apprendre les ficelles pour le transformer en un outil efficace.

Il s'agit là d'une liste partielle de nos nombreux accomplissements pour une période relativement courte, mais que restait-il à faire? Comment pouvons-nous donner aux infirmières en oncologie du Canada une voix plus puissante? Ce sont les questions que nous avons posées aux membres de l'Association, aux membres de notre conseil national et aux intervenants de l'extérieur de manière à élaborer notre plan stratégique. Nous avons dégagé cinq objectifs clés: 1) la nécessité de redévelopper notre infrastructure organisationnelle et d'assurer notre stabilité financière; 2) renforcer notre rôle de chefs de file en matière de politiques de santé et rehausser notre profil public; 3) diversifier les catégories d'infirmières concernées par l'adhésion à notre organisme et accroître le nombre de membres; 4) prendre les mesures qui s'imposent pour répondre aux questions relatives à la défense des intérêts des patients; 5) élaborer et mettre en œuvre une stratégie nationale en matière de formation qui appuierait et évaluerait l'élaboration de rôles, les connaissances et les compétences dans les domaines des soins infirmiers en oncologie adulte et pédiatrique du Canada. Tout cela représente un défi de taille, mais nécessaire si l'on veut que notre vision, devenir la voix reconnue des soins infirmiers en oncologie, soit plus à notre portée et devienne une réalité. Mais voilà une tâche qui requiert un leadership

véritable – et pas seulement chez les membres du comité exécutif ou du conseil national – mais aussi chez chacune d'entre nous, au sein des sections provinciales et des établissements. Vous serez les yeux, les oreilles, les mains et la voix de l'ACIO. Il va falloir que nous abandonnions nos anciennes manières de faire; selon moi, il est urgent que nous examinions les liens que notre infrastructure entretient avec la conduite de nos affaires et les opérations du conseil national.

Personnellement, je jouis d'une certaine abondance d'énergie, mais je peux vous assurer, après avoir exercé les fonctions de présidente pendant un an et quand on connaît la quantité de travail qui vient s'empiler sur nos bureaux ces temps-ci, qu'il m'est difficile de tout mener à bien tout en accomplissant les obligations de mon propre emploi. L'heure est-elle venue pour notre organisme d'opter pour un poste de soutien professionnel rémunéré tel que celui de directrice exécutive? Nous nous devons de remettre en question nos concepts démodés de représentation provinciale au conseil national. Pouvons-nous nous permettre d'y avoir une représentante de chacune des provinces? On retrouve ici le vieux dilemme canadien de péréquation et de régionalisation. Ne devrions-nous pas étudier la possibilité d'avoir trois régions: ouest, centre et est? Le Conseil national devrait-il entendre d'autres voix mise à part celle des soins infirmiers afin d'élargir l'étendue de ses domaines d'expertise? Je pense notamment aux domaines des finances, du marketing et du droit? Voilà donc quelques-unes des nombreuses questions sur lesquelles nous allons nous pencher en toute ouverture d'esprit, et cette réflexion marquera le début de la nouvelle phase du plan stratégique. Rien ne devrait être sacré: toutes les questions valent la peine d'être posées, et toutes les possibilités d'être examinées par le plus grand nombre de membres afin que cet exercice soit de la plus grande représentativité possible; ainsi, j'espère que chacune d'entre vous se demandera de quelle manière elle pourrait contribuer au processus.

Je crois que nous sommes parvenues à une bifurcation importante et qu'il nous faut choisir entre la volonté de changement – c'est-à-dire la voie de l'expansion, de l'énergie et de la visibilité accrue – et le maintien du statu quo et du rétrécissement inéluctable qui, d'après moi, se produira si nous n'allons pas de l'avant. Je suis sûre que nous ne serons pas à court d'excuses pour ne rien changer du tout. Le système des soins de santé traverse une période difficile, et il est naturel d'adopter une attitude pessimiste et de ressentir une grande fatigue. Mais n'oublions pas les enjeux: amélioration des soins prodigués

aux patients atteints de cancer et de la qualité de notre vie au travail. De toute ma carrière, il n'y a pas eu de moment plus propice que celui-ci car le public et le gouvernement nous prêtent l'oreille. Mais notre voix se doit d'être forte, ferme et unie! Je crois sincèrement que toutes les interventions et tous les buts que nous embrassons dans notre plan stratégique - que nous aborderons d'ailleurs durant l'AGA de mardi - peuvent se concrétiser grâce à l'engagement, à l'énergie et aux talents que possèdent les intervenantes des soins infirmiers en oncologie du Canada. Il nous faut retrouver un certain optimisme en sachant que c'est à nous qu'il incombe de façonner notre destin. Examinez votre propre carrière et vous verrez à quel point vous avez changé au fil des années, de même que le milieu des soins de santé.

Je ne crois pas que le discours que je suis en train de prononcer fasse partie des tâches que je m'attendais à accomplir à titre d'infirmière, mais j'ai réalisé que pour produire des changements de taille, chacun doit faire des efforts qui débordent de la pratique courante. Pour moi, l'ACIO est un organisme qui fera naître de tels changements. J'ai tiré - et je tire encore - mon inspiration des infirmières qui ont travaillé et travaillé à mes côtés que ce soit au sein du comité exécutif, du conseil national ou de comités. La quantité de travail produite est tout simplement extraordinaire; notre association compte presque 1000 membres alors que le nombre d'infirmières est actuellement en diminution au Canada; la conférence annuelle propose un programme impressionnant et les congressistes y assistent en grand nombre; notre situation financière s'est améliorée; le groupe CONEP chargé de la formation en soins infirmiers en oncologie présente la nouvelle version préliminaire de normes de soins; l'initiative sur la douleur cancéreuse inaugure son premier module éducatif; l'initiative sur la fatigue est relancée; nous nous sommes dotées d'un plan stratégique détaillé pour l'avenir. Mais, plus important encore, nos talents et, je crois, notre engagement nous ont permis de survivre à une année des plus difficiles, et même de trouver de nouvelles forces dans l'adversité.

Je tiens à remercier particulièrement Rose Steele et Heather Watson, coprésidentes de la conférence ainsi que le comité organisateur de Victoria et le BCONG (Groupe des infirmières en oncologie de la C.-B.). Grâce à leurs efforts, de merveilleuses journées nous attendent. Je peux vous dire qu'elles n'ont jamais douté un seul instant de leurs propres capacités et de celles de notre organisme. Leur travail et leur enthousiasme soutenu ont été pour moi une grande source d'inspiration.

Pour terminer, j'aimerais faire référence au discours que j'ai prononcé l'an dernier à Halifax. Depuis, on m'a demandé tellement de fois de reprendre cette histoire publiée par Kathleen Mooney dans le bulletin de la Oncology Nursing Society (**ONS News**, 11(10), Octobre 1996) que j'ai compris qu'elle véhiculait un message qui touchait de nombreuses infirmières. L'an dernier, je priais mes collègues de l'ACIO de bien vouloir suivre l'exemple des oies sauvages qui adoptent une formation en V lorsqu'elles effectuent leurs migrations: «de manière à ce que chaque oie puisse voler dans le sillage de la précédente. Grâce à cette technique, un vol d'oies pourra parcourir une distance supérieure de plus de 70 % à celle parcourue par une oie volant en solo. L'oie qui s'éloigne de la formation se rend très vite compte de l'aide et de la puissance qu'elle tire habituellement du sillage des autres lorsque, tout d'un coup, elle subit la pleine résistance de l'air. Les oies sauvages ont découvert la valeur d'une communauté unie et du choix d'une direction unique et précise. Suivons donc l'exemple des oies et efforçons-nous de renforcer les liens qui nous unissent. Volez en formation, invitez vos collègues à voler dans votre sillage, et faites connaître, d'une voix unie, les contributions de la profession infirmière à la prestation de soins de qualité aux personnes vivant avec le cancer. Les leçons que nous enseignent les oies portent également sur le leadership et le mentorat. Si l'oie qui vole en tête se sent fatiguée ou désorientée, elle se fait remplacer par une de ses condisciples et intègre la formation à un autre rang. Comme elles, nous nous devons de reconnaître notre interdépendance et de partager les responsabilités liées aux fonctions des dirigeants. Trop souvent, nous attendons de nos chefs de file qu'ils se penchent sur nos inquiétudes tandis que nous vaquons à nos propres occupations. Si nous voulons réussir, il faut que nous soyons prêtes à partager les tâches ardues et à mener la barque, tour à tour. Enfin, les oies sauvages peuvent nous apprendre bien des choses en matière de soutien et d'encouragement. Les oies à l'arrière de la formation cacardent afin d'encourager celles de l'avant à maintenir un certain rythme. Malheureusement, les infirmières ont tendance à critiquer les autres lorsqu'elles travaillent au sein d'un groupe abordant des questions difficiles. N'oublions surtout pas que lorsqu'elles sont en formation, ce ne sont pas des critiques mais bien des encouragements que les oies cacardent, car elles savent que c'est cette attitude qui s'avère la plus efficace.»

Et je peux vous assurer que depuis, des cacardements, j'en ai entendus... dans un large éventail de formes; depuis la ravissante oie en étain que Nancy a épinglé sur mon chemisier avant même que je ne reparte d'Halifax l'an dernier, aux messages

d'encouragement et d'appréciation reçus par courriel à propos de choses que j'avais écrites ou dites, en passant par les appels téléphoniques d'une foule d'infirmières que je n'avais jamais rencontrées individuellement mais qui voulaient partager une idée avec moi ou me poser une question au sujet de l'ACIO, des appels de membres du comité exécutif et du conseil national et d'infirmières me demandant comment j'allais et si j'avais besoin d'aide. C'est grâce à tout ceci que j'ai pu continuer mon travail et si je ne l'ai pas encore fait, je désire vous adresser tous mes remerciements pour votre soutien.

L'été dernier, vers la fin août, j'étais sur la plage adjacente à notre chalet familial et, au moment où le soleil se couchait majestueusement derrière les montagnes, un vol d'oies sauvages s'est fait entendre avant même qu'on puisse l'apercevoir. Mon mari s'est alors exclamé qu'il s'agissait de mes amies de l'ACIO qui m'encourageaient... et lorsque le premier vol est passé, les membres de ma famille qui connaissent dorénavant le nom de plusieurs d'entre vous, ont commencé à nommer divers membres de notre organisme au fur et à mesure du passage des oies sauvages! Mais notre plaisir ne s'est pas arrêté là car elles continuaient de passer au-dessus de nous, par vagues, petites ou grandes, rapides ou lentes, bien espacées ou au contraire compactes, certaines bruyantes, d'autres beaucoup moins... et voilà que j'ai eu une nouvelle vision... et j'ai réalisé que l'ACIO, tout comme ces vols d'oies sauvages, se compose de groupes divers: infirmières débutantes et infirmières chevronnées, gestionnaires et chercheuses, cliniciennes et formatrices, infirmières syndiquées et non syndiquées, membres du conseil national et membres de conseils provinciaux, infirmières préparées au niveau du diplôme ou d'un programme universitaire, infirmières spécialisées et généralistes, infirmières œuvrant en soins à domicile ou en milieu hospitalier. Comme Rose Steele et Heather Watson l'ont si bien exprimé dans l'invitation à la présente conférence, chaque infirmière apporte à la tapisserie une couleur particulière qui sera incorporée au motif d'ensemble. Notre devoir est donc de faire comme ces vols d'oies sauvages. De voler en formation, de garder le cap, de cacarder des encouragements mutuels, de crier pour que les gens sachent que nous arrivons, de nous assurer que notre voix est assez puissante pour que l'on nous entende encore longtemps après notre passage. Alors, tout au long de cette conférence, continuons de cacarder, de célébrer à tue-tête nos réalisations et de recruter des collègues qui joindront leur voix à la nôtre pour promouvoir les besoins des patients atteints de cancer et de leur famille.

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.

Bringing oncology research into the clinical setting: Meeting the standards

by Priscilla M. Koop

With the increasing focus on evidence-based practice, the need for excellent, clinically relevant oncology nursing research is greater than ever. Equally important is the need for that research to be incorporated into clinical practice. According to the Canadian Association of Nurses in Oncology/ l'Association Canadienne des Infirmières en Oncologie (CANO/ACIO) (1995), oncology nurses are responsible for participating in research (Standard IV: 2.7 - 2.9). What exactly do these standards mean and how can we make it possible for oncology nurses in all clinical settings to achieve these standards? Oncology nurses are extremely busy and the prospect of adding time for library work can be daunting. Few staff nurses have completed more than one or two introductory research methods and/or statistics courses, and most may feel unprepared to review the research literature critically. The purposes of this column are to review the three standards which relate to oncology nursing research and to suggest possible strategies for incorporating research into practice.

First, let us look at Standard IV: 2.8 which reads, "(Oncology nurses in any practice setting) demonstrate an attitude of critical reflection and inquiry regarding oncology nursing practice" (CANO/ACIO, 1995, p.22). This standard provides the basis for bringing the research literature into clinical practice. Oncology nurses who are "critically reflective" ask lots of questions - of their colleagues, of the literature, and of themselves. At conferences, they attend as many sessions as possible and ask questions of the speakers. They talk with other nurses about what they have read and heard (and their perspective is not always flattering to the researchers!). They are likely to speak up at shift report or during coffee breaks with "Why?" questions. They try to understand why we follow certain routines and not others. They try to square practice with the

stated mission and philosophy of the institution.

How do oncology nurses develop these attitudes within themselves? Ideally, the educators and preceptors encountered in one's nursing education will have fostered an inquiring mindset. Lucky graduates will have taken their research methods and statistics courses from educators who facilitated the development of curiosity and confidence within their students. Another way to develop this mindset in one's self is to spend as much time as possible with peers and mentors who display these attitudes in their professional lives. Finally, we need to simply begin the habit of asking ourselves why we provide and organize our care the way we do. "Is there a better way to do this?" is something we need to ask ourselves on a regular basis.

Standard IV: 2.7 provides some guidance about what to do with the questions which we ask ourselves: "(Oncology nurses in any practice setting) are knowledgeable about oncology nursing research and utilize the findings in practice." The idea of keeping up with the field of oncology nursing research

is quite daunting when one realizes how many journals are devoted to oncology nursing or related areas. Journal clubs are a possible strategy to keep in touch with the oncology nursing literature and can be run in a variety of ways. If the journal club is organized topically, then each member brings one article on a previously agreed-upon topic and contributes both clinical insights and the contents of that article to the discussion. Alternatively, articles can be photocopied and distributed prior to the meeting and then all members discuss them from a common base. Photocopies can be made for personal use without violating copyright.

Clinical rounds are another terrific idea for bringing the research literature into clinical practice. On a recent trip to Montreal, I spent time with oncology nurses in several hospitals and saw some innovative ideas for handling clinical rounds. At one of the clinical rounds, three pairs of nurses each presented a patient with complex clinical issues. They provided a history of the patient and family, presented relevant literature to the clinical situation, and then conducted a discussion of the issues that they saw as unresolved. The discussion was thoughtful, insightful, and relevant to the participants as well as the presenters. One of the presenters commented that the discussion had facilitated new ways of thinking about clinical situations.

CANO has a new head office address:

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If you do not have access to a journal club or clinical rounds, there are other strategies for reading the research literature and thinking about how it might facilitate clinical practice. The **Canadian Oncology Nursing Journal** offers research-based articles and is an excellent place to find answers to clinical questions. Many oncology nurses subscribe to other journals as well. The internet is another source of research literature. Most databases (e.g. CINAHL, CancerLit) offer abstracts or full texts of published articles. If you have a computer and access to the internet, you can do the literature searching and reading from the comfort of your home. Libraries, whether based in a clinical or educational setting, typically have computers with access to the internet. If you weary of the hustle and busyness of your working environment, the hospital library also offers the wonderful side attraction of being a peaceful place for a break.

The second part of this standard focuses on utilizing research findings in clinical practice. The literature on using research in practice tends to advise syntheses and thorough critiques of a whole body of literature before changing practice (e.g. Titler, 1998). This advice is sound and is meant to avoid the premature adoption of tentative findings into practice. Carried to a logical extreme, however, this advice might suggest that nurses not bother to read any research literature other than a systematic literature review. I think that would be a mistake. Small descriptive studies and qualitative research, although they may not meet inclusion criteria for large systematic literature reviews, may nonetheless offer new insights into practice and are, therefore, of potential value to the oncology nurse. I

encourage oncology nurses to read the oncology nursing literature with an inquiring mind and to weigh current practices with the ideas evident in the literature. I would also encourage oncology nurses to allow the ideas to affect the way they think about their practice - to explore (within the limits of established policies and the principle of safe practice, of course) the various ways of offering excellent and thoughtful care to their patients.

Standard IV: 2.9: "(Oncology nurses in any practice setting) participate in research activities to expand the body of knowledge in oncology nursing." Oncology nurses can participate in research in a variety of ways and can play a range of roles on the research team. Staff nurses may participate in research by providing information sheets to patients or family members as a way of inviting them to participate in ongoing oncology nursing research. Nurses may help more directly with respondent accrual by verbally inviting patients and family members to participate as respondents. This assistance can be of tremendous value, as nurses in clinical practice are familiar with their patients and can time the invitation to give patients and family members an opportunity to think about whether or not they wish to participate in any particular research project. Staff nurses may also collect data as research assistants or they may be involved as co-investigators on research projects. Whatever the research activity and the researcher role, staff nurses in oncology have tremendous assets for the conduct of oncology nursing research.

I recommend that oncology nurses find out about ongoing nursing research in their clinical settings and explore ways to get

involved. Participating is a good way to learn more about the process of research. As you get involved and learn the process, you may become more active in the research process by posing questions that need to be researched.

In this column, I have reviewed the three CANO/ACIO standards that relate to involvement in research by nurses in any clinical setting. I have recommended strategies for meeting these standards. There are many additional strategies that are currently being used to bring oncology nursing practice into the clinical setting. I would be pleased to hear about the strategies which you currently use. I would be pleased to share these strategies with your colleagues across Canada. Please write to me and let me know what works for you. ✪

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- go to the Canadian Oncology Society's (COS) web site, 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
- if you want to obtain a membership form or learn more about membership benefits, click on "Membership Application and Benefits"
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THE 2000 HELENE HUDSON MEMORIAL LECTURE

12TH ANNUAL CANO CONFERENCE - OCTOBER 2000

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Decisional role in seriously ill hospitalized patients near the end of life: The patient's and provider's perspective

by J.E. Tranmer and D. Heyland

Abstract

Decisions about whether or not to implement life-sustaining therapies are complex and are becoming more so as the ability to prolong life with advanced technologies and care increases. The objectives of this study were: (1) to determine seriously ill hospitalized patients' preferences for decisional role with respect to decisions about life-sustaining treatments, and (2) to determine if providers were aware of patients' preferences.

This prospective, descriptive pilot study was conducted at an Ontario teaching hospital. One hundred and seventeen seriously ill adult patients admitted with cancer and non-cancerous conditions participated in a structured interview. Fifty-three nurses and 63 physicians responsible for the care of the participating patients also participated. Patients and providers were asked similar questions about end-of-life discussions and preference for decisional responsibility for life-sustaining treatments.

Most patients (n=89, 77%) had thought about end-of-life issues and were willing to discuss these with their physicians and nurses, but few (n=37, 37%) reported such discussions. Preferences for decisional role varied; most indicated a preference for a shared role (n=80, 80%) and there were no differences in patients with or without cancer. Generally, both physicians and nurses were not aware of or did not determine accurately patient preferences for decisional role.

The findings from this study show that seriously ill hospitalized patients have thought about and are willing to share in discussions about end-of-life care with their providers, yet many have not.



Helene Hudson, 1945-1993

Statement of issue

In Canada, over 70% of deaths occur in the hospital. Patients with a primary diagnosis of cancer account for approximately 30% of these deaths. With the ability to prolong life with advanced technology and care, patients with primary and secondary diagnoses of cancer (and their family members) are, increasingly, confronted with decisions about whether or not to implement life-sustaining therapies. These are difficult, value-laden treatment decisions. Preferences for treatment are often unknown or not sought. Many studies examining end-of-life issues describe responsibility for these decisions (i.e., the decision to treat or to withhold or withdraw treatment) from the physician's perspective. Although several position papers have been written, very little research has been conducted investigating the role of nurses in end-of-life care and end-of-life decision-making.

Recent studies of end-of-life care suggest that improvements in communication and the decision-making process may lead to improvements in quality end-of-life care. A large five-centre study conducted in the United States, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) enrolled over 9,000 patients. The objective of this two-phase study was to improve end-of-life decision-making and reduce the frequency of mechanically supported painful and prolonged processes of dying. In phase one, the process of decision-making and patient outcomes were described and observed in 4,301 patients. There were shortcomings in communication and evidence of aggressive life-sustaining treatments: only 47% of physicians knew patients' preferences, 46% of do not resuscitate (DNR) orders were written within two days of death, 38% of patients had a 10-day ICU stay, and many experienced moderate to severe pain in their last days of life. The findings from phase one suggested that management was most impacted by poor physician-patient communication. In phase two, a nurse-based intervention was designed. A "skilled" nurse made many contacts with the family, patient, and physician to elicit preferences, improve patient and family's understanding of outcomes, encourage attention to pain control, and, overall facilitate advance care planning and communication. This study relied solely on the nurse as a communicator, facilitator, and advocate to improve the decision-making process. There were no significant differences in the measured clinical or economic outcomes. The apparent failure of this intervention strongly suggests that there are other more powerful determinants of the decision-making process that are not completely understood.

Therefore, the purpose of this research was twofold: (1) to determine seriously ill hospitalized cancer and non-cancer patients' preference for decisional role with respect to end-of-life decisions, and (2) to determine if their providers (nurses and physicians) were aware of their preferred role. We hypothesized that seriously ill hospitalized patients would prefer to defer or share the responsibility about end-of-life treatments to their health care providers and that cancer and non-cancer patients may have different experiences as the illness trajectory for cancer is more predictable and, historically, cancer patients have received more formal palliative and advance care planning. Secondly, we hypothesized that most providers would be unaware of patients' preferences. The long-term goal of the End-of-Life Research

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Working Group (EOLRWG) is to develop and evaluate processes that enhance decision-making around end-of-life issues. Health care providers (nurse and physician) are essential for the process. Ultimately, with better decision-making processes, the effectiveness and quality of end-of-life care will be enhanced.

Background literature

End-of-life decision-making

Our current understanding of end-of-life decision-making stems from published conceptualizations and empirical results of studies of health care decision-making, predominantly studied in other patient populations. Several factors affect the process and/or outcomes of clinical decisions near the end of life. Intrapersonal factors include each patient's unique personal, physical, psychological, and sociocultural characteristics such as health status, patient preferences, their health care decision problems, beliefs, and values. The interpersonal factors are those factors that will influence the real world decisional interactions and the process of information exchange, deliberation, and, finally, the decision. Provider characteristics such as knowledge and skill, beliefs, and values will influence the nature and extent of the interactions. These interactions are influenced by the contextual nature of the environment in which they take place. Discussions about end-of-life care may be very different in a home setting versus an acute care setting.

Health care decision-making is interactional, which is both a strength and a weakness. Interactions are time- and energy-consuming and assume that both the provider and patients have an investment in the process and that there are treatment options available. With each interaction, there is a decision-making process. Charles and colleagues (1997) define three role models and three distinct analytic stages to the decision-making process: information exchange, deliberation about treatment options, and deciding on which treatment option. These processes will vary across patient-provider interactions depending on the nature of the patient-provider relationship. Information exchange refers to the types and amount of information exchanged. Depending on the model, the amount and direction of flow of information will vary. For example, when a patient assumes a passive role and the provider an active role, the flow of information is largely one way, from the provider to the patient. The provider communicates the minimum amount of information to the patient to satisfy the requirements of "informed consent." In the informed model, the flow is again from the provider to the patient, but this time the provider communicates all information desired by the patient to help him or her make the decision. In a shared decision-making model, the information exchange is two-way. The provider shares information relevant to making the decision, the patient provides information on values, lifestyles, fears, and preferences. The process of information exchange may be critical to decision-making near the end of life.

Research documenting the preferred role of seriously ill hospitalized patients is limited. Patients' perceived and desired role in the decision-making process has been studied more in other patient populations, most notably in ambulatory cancer patients. Compared to the general population, cancer patients prefer a more passive role in the decision-making process. While these studies of patients' preferred role are informative, they may not be generalizable to cancer (or non-cancer) patients making end-of-life treatment decisions (contrasted with cancer-related treatment decisions).

An organizing framework for end-of-life decision-making.

We have attempted to integrate many of the concepts into an organizing framework to guide this study (and others) conducted by the End-of-Life Research Working Group (Heyland, Tranmer, & Feldman-Stewart, 2000). The framework consists of four "units of study": a) provider, b) patient, c) decision-making process, and d) outcome. It should be emphasized that this is an organizing framework and it cannot be overstated that conceptually, decision-making, especially near the end of life, is complex. The interactions are continuous, involve multiple providers and family members,

occur within a complex social environment of often conflicting priorities and values, and the decisions are value-laden and final. While we conceptualize the patient-provider interactions as one of three models (passive, collaborative, active) the models should not be construed to represent rigid processes or events. Patients and providers may move from one model to another from one interaction to the next or even within one interaction. For example, as a physician operating in an active role senses that his patient requires more information and participation in the decision-making, he may move to a more shared decision-making model. The optimal outcome(s) of the process will be unique for each individual and, consequently, are difficult to define and measure.

The nursing role in end-of-life decision-making

If health care and end-of-life decision-making are thought of as a continuum, anchored by the patient at one end desiring full responsibility and control and the physician (provider) at the other end dictating clinical decisions about patient care, we hypothesize that the nurse functions in several roles as a facilitator, interpreter, and clarifier, and is often a filter through which communication occurs between the physician and patient. The nurse as the mediator interprets for the physician and advocates for the patient and family. Thus, if the nurse is participating by mediating patient preferences, then his/her perception of the degree of responsibility for patient decision-making should be congruent with that of the patient.

Very few research studies have addressed the role of the nurse in end-of-life decisions, although some studies have addressed nursing attitudes towards end-of-life issues. Gaps in the decision-making process are evident and those that may involve nurses have not been adequately addressed. A recent study by Wilson and colleagues (1997) comparing interns' and attending physicians' abilities to predict end-of-life treatment choices of seriously ill hospitalized patients found that physicians often learned of the patients' CPR preferences from sources other than the patients. No specific data were given that quantified 'often.' No indications were given as to whom these sources were, although it is possible that one of the main sources was the patient's nurse. A study by Baggs (1993) found that the amount of collaboration between nurses and ICU house staff in the decision to transfer a patient out of the ICU, as reported by nurses, was a statistically significant predictor of risk of a negative patient outcome. As the collaboration increased, as reported by nurses, the incidence of negative patient outcomes decreased. Collaboration, as reported by house staff, was not statistically associated with patient outcomes. Although this study did not look especially at end-of-life decisions, the results indicate that the role nurses play in clinical decision-making can impact patient outcomes.

The aim of phase two of the SUPPORT study was to improve end-of-life decision-making and reduce the frequency of a mechanically supported, painful, and prolonged process of death. In this randomized controlled study, physician groupings were randomized to receive the intervention or not. The intervention consisted of nurses: (1) providing prognostic information to physicians; (2) eliciting patient preferences; (3) encouraging physician attention to pain control; (4) facilitating advanced care planning; and (5) facilitating physician-patient communication. Although the SUPPORT trial failed to achieve statistical significance on any of the five primary outcomes: physician understanding of patient preferences; incidence and time of documentation of do-not-resuscitate orders; the amount of pain experienced by patients; time spent in intensive care unit, comatose or receiving mechanical ventilation before death; and hospital resource use - one cannot conclude that there is no role for nurses in end-of-life decisions.

Oddi and Cassidy (1998) in a critical commentary of the SUPPORT trial suggested that the poor outcomes might have been related to the investigators' inadequate understanding of, and consequently the incorporation of the nursing skill and knowledge into the project design and intervention. Nurses were to independently develop their role, similar to "nurse specialists." The nurse selection criteria, background education, preparation, and

responsibilities varied between sites. Nurses may have failed as communicators because their information was not valued or perceived as credible. Nurses may have failed in their role as patient advocates because of a lack of assertiveness and support by the health care team. Nurses were caught in the middle between families and patients and the physicians - there was little evidence of collaboration. However, Oliverio and Fraulo (1998) favourably commented on their role as nurse clinicians. They stated that they came to understand the complexities and fears of patients and families in this process and perhaps it was these complexities that explain why the communication efforts seemingly demonstrated no benefit. They felt strongly that it was the nursing role to advocate for appropriate care in accordance with patients' and families' preferences in conjunction with the clinical judgment of the health care team. The nursing role was to make sense of the complex factors, such as high technology, hope, futility, and the burden of the decisions. They also suggested that outcomes related to process and comfort and caring may be more appropriate to measure.

Summary

End-of-life decision-making for seriously ill hospitalized cancer and non-cancer patients is complex. Recent research suggests that our efforts to improve the care near the end of life have not been successful. Specifically, the nursing role remains underdeveloped and underutilized. Therefore, the purpose of this study was to explore important aspects of end-of-life decision-making in seriously ill hospitalized cancer and non-cancer patients from both a patient and a provider perspective.

Research questions

In this study we posed three research questions:

1. What role do seriously ill hospitalized patients wish to assume in decisions about life-sustaining treatments?
2. Is there a difference in preferences for decisional role in patients diagnosed with cancer or non-cancerous conditions?
3. Are health care providers (nurses and physicians) aware of patients' preferences for decisional role and if so what is the congruency?

Research method

The study design was a case-specific, cross-sectional survey administered in face-to-face interviews. The study was conducted in an acute care, university-affiliated hospital in southeastern Ontario. The study population consisted of those patients admitted to the Kingston General Hospital who met the patient inclusion/exclusion criteria, the patients' assigned nurse, and the patients' attending and resident physicians.

Patient inclusion criteria required that patients were age 18 years or more; were admitted to hospital for medical reasons; had one or more of the following co-morbidities: (a) chronic obstructive lung disease (COPD) determined by the presence of two or more of a baseline pCO₂ of ≥ 45 torr, cor pulmonale, respiratory failure within the last year, or forced expiratory volume of ≤ 25%; (b) congestive heart failure (CHF) determined by New York Heart Association Class IV symptoms of ventricular function ≤ 25%; (c) cirrhosis determined by diagnostic imaging or esophageal varices and hepatic coma or class B or C liver disease, or (d) metastatic cancer (admitted with a complication); were expected to stay in hospital 72 hours or more; and could speak English. Patients with psychiatric illness, those who were expected to have difficulty in communication (language, cultural, or cognitive barriers), and those who were facing imminent death were excluded from the study. The patient inclusion criteria for the study sample were chosen to reflect the inclusion criteria used in the SUPPORT study. Patients whose condition may deteriorate to the point where they may be at risk of facing end-of-life decisions and whose probability of survival at six months was 50% were included in the sample.

Each study subject's assigned nurse, responsible resident, and attending physician were approached to participate in the study. The assigned nurse was the nurse assigned to the patient on the day of the interview. The attending physician was the staff physician who was responsible for the patient's in-hospital medical care at the time

the survey was administered to the patient. The most responsible resident was the senior resident assigned to the care of the patient.

Measures

We obtained information from patients using a structured questionnaire administered by a research assistant. The questionnaire consisted of a preamble explaining the study objectives; questions to determine the patient's role in making decisions; questions determining with whom the patient feels comfortable discussing end-of-life issues; and a section to collect demographic data. We did not use the card sort approach as originally designed by Degner and Sloan (1992), as we were concerned about the time required to sort responses and we also wanted to use the same methodology with the physicians and nurses. The measurement tool for physicians and nurses consisted of a subset of questions of the questionnaire given to the patient. The health care provider questionnaire assessed the physicians' and nurses' perception of the role they thought the patient would desire with respect to end-of-life decisions. We also provided an opportunity for both patients and providers to comment on their responses.

Data collection

All attending physicians were informed about the study and endorsement was sought for involvement of patients assigned to their care. Most attending physicians agreed to participate. A small number of physicians raised concern about the focus of the study on end-of-life issues, especially with "their patients" with whom they may not have discussed these issues. We attempted to reassure physicians that we were exploring the process of decision-making in an attempt to describe strengths and gaps and that we were only focusing on preferences for decisional role and not actual preferences for care.

Patients were approached for participation if they met the inclusion criteria and had been in hospital for at least three days. After patient consent was obtained, the research assistant conducted the interview. The nurse assigned to the patient on the day of the interview, the most responsible senior resident physician, and the attending physician were given a questionnaire to complete for each patient enrolled in the study. The research protocol was reviewed and approved by the Kingston Health Sciences Research Ethic Board.

Table One: Patient characteristics of sample

Characteristic	n	Cancer	n	Non-cancer
Gender	56		61	
Female		30 (54%)		27 (44%)
Male		26 (46%)		34 (56%)
Mean age	56	66 (SD 12)	61	72 (SD 18)
Expired within six months of interview*	43	74% (32)	37	54% (20)
ICU admission	56	4 (7%)	61	18 (30%)
Documented EOL discussions	56	17 (30%)	61	20 (33%)
Documented EOL order	56	20 (36%)	61	20 (33%)
Palliative care consult	56	24 (43%)	61	3 (5%)
Education	52		54	
Less than high school		17 (33%)		22 (41%)
Completed high school		14 (27%)		16 (30%)
More than high school		21 (41%)		16 (30%)
Living arrangements	52		54	
On own		10 (19%)		17 (31%)
With family		38 (73%)		33 (60%)
Supervised residence		4 (9%)		4 (9%)

* Data only available on patients enrolled in first six months or those who expired before July 2000.

Results

Sample

Patient recruitment for this study began in July 1999 and provider recruitment in February 2000 and will continue for another six months. As of July 2000, the time of this report, the patient participation rate was 57% (122/215). The most common reason for non-participation was the patient's desire not to be in a study. The response/participation rate for nurses, residents, and attending physicians was 86% (46/53), 64% (19/29), and 77% (26/34) respectively. For the purpose of this report, the attending and resident responses are combined into physician responses.

Patient characteristics

Results are reported on the first 117 patients enrolled in the study (see Table One). Patients enrolled in the study were elderly. Of those patients who were enrolled in the beginning six months of the study, 74% of patients with cancer and 54% of patients with non-cancerous conditions have expired. More of the patients with COPD and congestive heart failure had ICU admissions in comparison to the cancer patients. More cancer patients had received palliative care consults. However, only one-third of patients in both groups had recorded discussions about end-of-life (EOL) care or an EOL order on their patient record. Most patients either lived on their own or with another family member. In this sample, 58% (62/107) were married, 26% (28/107) divorced, and the remaining 15% (17/107) were either single or widowed. Most were retired (81%, 87/107).

Nurse characteristics

Nurses (n=42) were employed on the medical surgical units. Twenty-nine per cent were in part-time positions, 60% in full-time positions, and the remaining 11% in temporary part-time or full-time. Nurses in this sample had worked for an average of 11 years with a range of work experience from one month to 33 years. In this hospital,

patient assignment is done on a shift-to-shift basis - there is no primary nurse assignment. A single clinical nurse specialist, palliative care, provides important support to patients and families.

End-of-life discussions

In the first part of the interview, patients were asked the questions listed in Table Two. Most patients (77%, 89/116) have thought about treatments they would wish to receive if they developed a life-threatening complication. However, similar to what is recorded in the patient record, 37% of patients (43/116) reported having these discussions. Most are willing to discuss these issues with their physician. Those patients who wished not to discuss end-of-life care stated that they would discuss these issues with others (i.e., family physician) or they did not feel there was a need to discuss now. Very few discussions about end-of-life care with the nurse or other health care providers were reported (n=18, 16%). However, many patients expressed a willingness to talk with nurses. Over one-half of the sample reported that they had some form of advance directive - usually located outside the hospital (n=66, 57%).

Preference for decisional role

In this sample, there was no difference with respect to desire for decisional role in patients with cancer and those without (see Table Three). The preferences for role varied. The majority of patients expressed a desire for a shared or a more active role in making decisions about life-sustaining treatments. Patients provided some very clear comments about their views. A patient who expressed the desire for a shared role reported:

"It makes more sense - I need to have the discussion between the doctor and myself as he would know the best treatments for me. He is a professional and could tell me what option was best and I would respect his/her opinion."

A patient who expressed the desire for a more active role reported, "This is my body and my decision. I want control - living and dying is up to the individual." Fewer patients, but still a substantial number, wished the physician to take more of a role. They stated, "I am not a

Table Two: End-of-life discussions

Questions	n	Cancer	n	Non-cancer
Have you thought about the kinds of treatments you want to receive if you develop a life-threatening complication?	56	43 (77%)	60	46 (77%)
Have you had any discussions with your physician, during this hospital stay, about your wishes?	56	21 (38%)	60	22 (37%)
• If no, would you be willing to discuss your wishes with your physician?	35	25 (71%)	32	26 (82%)
Have you had any discussions with your nurse or other health care providers, during this hospital stay, about your wishes?	56	7 (13%)	60	11 (18%)
• If no, would you be willing to discuss your wishes with other health care providers?	49	31 (63%)	49	30 (61%)
Are your wishes written down or recorded somewhere?	56	31 (55%)	60	35 (58%)

Table Three: Preferences for decisional role

Patients prefer:	Cancer (n=50)	Non-cancer (n=57)
To leave decisions to their doctor	5 (10%)	7 (12%)
Have the doctor make the final decisions but seriously consider their opinion	4 (8%)	6 (11%)
Have the doctor share responsibility for decisions	16 (32%)	21 (37%)
To make the final decisions after seriously considering their doctor's opinion	17 (34%)	13 (23%)
To make the decisions	8 (16%)	10 (18%)
Patient preferences for family member's role:		
Leave decisions to their doctor	5 (10%)	9 (16%)
Have the doctor make the final decisions but seriously consider their opinion	1 (2%)	7 (12%)
Have the doctor share responsibility for decisions	19 (38%)	17 (29%)
Make the final decisions after seriously considering their doctor's opinion	19 (38%)	15 (26%)
To make the decisions	6 (12%)	9 (16%)

doctor - I am unable to make that decision - he must know what he is doing." We also asked what role patients would wish their family member to assume if they were not able to participate. The same trend of responses was noted.

Providers' awareness of preferences

The provider responses followed a similar pattern to that of the patients (see Table Four). However, we provided an opportunity for the providers to indicate that they could not determine patients' preferences. Forty-six per cent of the nurses in the sample indicated that they did not know the patient well enough to determine preferences for decisional role with respect to decisions about end-of-life care. Fewer physicians reported this "unawareness", however, fewer physicians responded which may indicate that unresponsiveness is similar to unawareness. Nurses commented that, "they were only just assigned the patient," "they did not think they knew the patient well enough to discuss these issues," "the patient was stable now and there was no need to talk about these issues." Physicians also stated that the patient was currently stable and there was no need to talk about end-of-life care. At times they did not know the patient well enough - i.e., they were the "covering" oncologists for inpatients.

The degree to which each patient and nurse agreed upon the preferred role was analyzed. An active role was coded if patients or providers indicated that the patient wished to decide with or without physician input, the collaborative role included the shared category, and the passive role included the categories in which the patient indicated that they wished the physician to decide either on his/her own or after consideration of their opinion. This categorical breakdown is similar to the one used by Degner and Sloan (1992) in their categorization after the unfolding of preferences using the card sort technique. Nurses agreed with patients 19% of the time, however when nurses assessed patient preferences the agreement was 38% (8/21). Patients reported more of a preference for an active role in comparison to a passive role. However, the actual discrepancy was small (i.e., a difference of one level).

Most nurses (95%, n=44) and 36% (n=16) of the physicians reported that they had no discussions with patients about life-sustaining treatments. Twenty-three per cent of the physicians (n=10) reported that they had discussed life-sustaining treatments with the patient and the patient agreed that they had done so. A substantial proportion of the physician population (30%, n=13) reported that either they had talked with the patient and the patient said they had not or, conversely, the physician had no discussions and the patient said they had. Overall, in this sample of patients there was a paucity of communication around end-of-life treatments.

Summary of findings

Patients near the end of life differ with respect to role preference, however most (80%, n=80) prefer a shared process and active involvement in the decision-making. There were no differences in role preference between patients whose primary diagnosis was cancer in comparison to patients whose primary diagnosis was non-cancer related. Nurses (and physicians) in this acute care setting were not aware of or misinterpreted patients' preferences for decisional role. Common themes emerged: patient was not critical enough, only just assigned, role ambiguity, and lack of communication processes.

Study strengths and limitations

The major strength of this study is that our sample accurately reflects patients who are near the end of life, as over 50% of patients enrolled in the first six months have expired. The second strength of this study is the use of comparison groups. In many hospitals, patients with cancer are often admitted with complications related either directly or indirectly to their cancer or other underlying conditions. Therefore, it was important to determine the similarities and differences in seriously ill hospitalized patients. Finally, this study reflects the real life world of the providers and the contextual influences of a tertiary teaching hospital, including multiple caregivers and patient assignments.

The major limitation of this study is the use of a cross-sectional survey to measure a complex process such as decision-making. We focused on certain aspects (i.e., decisional role) of decision-making at one point in time. While this produced some important findings, further longitudinal research could explore the influence of important determinants of effective decision-making during the end-of-life phase. Indeed, during the interviews the research assistants often commented on the "richness" of some of the interviews. Finally, the provider sample size is small. Data will continue to be collected until there is a large enough sample to generalize the findings.

Discussion

The findings of this study show that in this sample of seriously ill hospitalized patients, most have thought about and are willing to discuss end-of-life treatments with both physicians and nurses, yet many have not. Nurses were not comfortable discussing these issues as they perceived this to be the physician role, and they were only just assigned the patients. The physicians often stated that "someone else" should do this or that the patient was not critical enough at this point. The research literature reports concerns about the late and inappropriate timing of end-of-life discussions, in particular referrals to palliative care or institution of EOL orders. The findings from this study support this concern. Unfortunately, most patients with the diagnostic conditions and criteria used in this study died within six months. Providers do not know if this is the sentinel admission that may be the patient's last - thus we should engage in end-of-life discussions before the critical end points of uncontrollable pain or symptoms or inevitable death. We have prognostic criteria and willing patients (and families) but, consistent with the acute care culture, we wait until there is a crisis. Thus, there is a need to focus end-of-life care beyond the "very end of life."

Patient preferences for role varied, but many patients expressed a desire for sharing in some way the information exchange and deliberation and assuming of decisional responsibility. This was not what we expected as we hypothesized that patients, because of their serious illnesses, would defer responsibility to the care provider. There are two possible explanations for this finding. Firstly, the decision to end life is "high stake" and thus patients (and families)

Table Four: Providers' awareness of preferences

This patient prefers to:	Nurse (n=46)	Physician (n=45)
Leave decisions to the doctor	1 (2%)	3 (7%)
Leave decisions to the doctor but consider their opinion	3 (7%)	3 (7%)
Decide together	7 (15%)	14 (31%)
Make the decision but consider doctor's opinion	12 (26%)	19 (42%)
Make own decisions	2 (4%)	2 (4%)
Do not know	21 (46%)	4 (9%)
Patient - provider agreement:	Nurse-patient dyads (n=42)	Physician-patient dyads (n=45)
Patient and provider agree on preferred roles	8 (19%)	9 (21%)
Patient wished a more active role than provider determined	8 (19%)	17 (40%)
Patient wished a more passive role than provider determined	5 (12%)	13 (30%)
Provider not able to determine	21 (50%)	4 (12%)

more than likely feel strongly about how they wish this stage of life to unfold. They want to be involved and heard. Why do patients willingly choose a passive role? Is this their desire or a reaction to their feelings of vulnerability and loss of control or, conversely, could it be related to a sound trust in the decisions made by the physicians and others? It does not seem to be related to the severity of their illness or their inevitable death. Secondly, patients may perceive that there are no real options - either life or death. This is not the case with other medical or health care decisions. Furthermore, many of these patients had chronic conditions and were knowledgeable of their own condition and their experience. They could make an informed decision.

The majority of nurses in this sample either were unaware of or misinterpreted the patients' preferences. Based on position papers and policy statements, we assumed that a nurse would function as a clarifier, advocate, and mediator for patients with respect to decisions about end-of-life care; however, in this study, in this acute care setting, this was not the reality. In this hospital, nurses are assigned to patients on a shift-to-shift basis and communication about patient needs and care often focuses on the immediate needs - there is little emphasis and perhaps opportunity in a shift assignment to proactively discuss care issues that are not directly related to immediate care needs. However, many hospitals employ a number of strategies to address some of these gaps - discharge rounds, palliative care specialists, and advance care planning. Unfortunately, as evident in the results of this study, they are administered to a few (i.e., few palliative care consults to cancer patients and none to non-cancer patients) or very close to the end of life. It is concerning that some nurses are abdicating all of the responsibility of discussions about end-of-life care to the physician. Nurses do have a professional role and mandate in this regard, and hospital (and other) professional administrators need to provide the necessary supports for nurses to engage in this care. Oliverio and Fraulo (1998) offered some suggestions based on their experience in the SUPPORT trial. They recommended that (a) death needs to be understood as natural and inevitable; (b) discussions about end-of-life care issues need to occur early in all settings and be communicated thoroughly; (c) nurses need to be aware of the burden that family members experience when participating in end-of-life decisions and intervene to minimize the burden; (d) there is a need to consider the creation of cultures (and perhaps units) that support care near the end of life; and (e) patients need to be reassured that they will receive quality care regardless of decisional preferences. They also recommended that a role similar to the SUPPORT nurse be implemented in hospitals. We would recommend the development and evaluation of multi-faceted strategies to improve care near the end of life. This could include heightening awareness about end-of-life issues; increasing nursing knowledge and skill with respect to quality care issues near the end of life; supporting and mentoring nurses in patient advocacy roles; establishing methods of communication that are reliable and feasible; and establishing strategies that both providers and patients can engage, as they desire, in important decisions about care.

Historically, nurses have provided compassionate care to dying patients and their families. We need to extend this care to patients as they approach the end of life. Patients are willing to be involved. Nurses in the acute care setting need to incorporate end-of-life care processes into their repertoire of knowledge and skilled care that they normally provide to seriously ill hospitalized patients. The challenge for nurses (and physicians) is to provide this care in an acute care environment that is ever-changing, complex, and treatment-oriented. 🍀

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PARRAINÉE PAR AMGEN CANADA

Le rôle décisionnel chez les patients hospitalisés gravement malades en fin de vie : la perspective du patient et celle du soignant

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Abrégé

Les décisions concernant la mise en œuvre ou non de traitements de survie sont complexes et le deviennent toujours davantage à mesure que la médecine est de plus en plus capable de prolonger la vie en faisant appel à des technologies et des soins de pointe. Cette étude avait pour objectifs: (1) de déterminer les préférences des patients hospitalisés gravement malades en matière de rôle décisionnel lié à l'utilisation de traitements de survie, (2) de déterminer si les soignants connaissaient les préférences de leurs patients.

Cette étude pilote prospective et descriptive s'est déroulée dans un hôpital d'enseignement de l'Ontario. Cent dix-sept adultes gravement malades et hospitalisés à la suite de cancer et d'autres maladies ont participé à une entrevue structurée. Cinquante-trois infirmières et 63 médecins qui étaient chargés des soins aux répondants ont également participé à l'étude. On posait des questions semblables aux patients et aux soignants sur les discussions relatives à la fin de vie et sur leur préférence quant à la responsabilité décisionnelle visant les traitements de survie.

La plupart des patients (n=89, 77 %) avaient déjà réfléchi à des questions relatives à la fin de vie et étaient prêts à en discuter avec leurs médecins et infirmières, mais ils étaient peu nombreux (n=37, 37 %) à signaler de telles discussions. En ce qui concerne le rôle décisionnel, les préférences variaient, la majorité des répondants indiquant une préférence pour un partage de la prise de décision (n=80, 80 %) tandis que l'on n'observait aucune différence entre les réponses des patients atteints de cancer et les autres. En général, ni les médecins ni les infirmières n'étaient au courant des préférences de leurs patients en la matière, ou étaient dans l'impossibilité de les déterminer correctement.

Les résultats de cette étude montrent que les patients hospitalisés gravement malades ont réfléchi aux soins en fin de vie et qu'ils sont prêts à en discuter avec leurs soignants, mais que, dans bien des cas, ces discussions n'ont jamais lieu.

Énoncé du sujet

Au Canada, plus de 70 % des décès surviennent à l'hôpital. Et les patients ayant un diagnostic primaire de cancer représentent environ 30 % de ces décès. Les technologies et les soins de pointe permettent désormais de prolonger la vie, et les patients ayant un diagnostic primaire ou secondaire de cancer (et leurs proches) doivent prendre, de plus en plus fréquemment, des décisions sur la mise en œuvre de traitements de survie. Il s'agit là de décisions thérapeutiques pénibles, reflétant les valeurs personnelles. Souvent, on ne connaît pas les préférences des patients en matière de traitement, ou on ne cherche même pas à les connaître. De nombreuses études explorant des questions relatives à la fin de vie décrivent la responsabilité décisionnelle (c.-à-d. la décision d'administrer un traitement ou au contraire de le refuser ou de l'interrompre) depuis la perspective du médecin. Quoique quelques exposés de position aient été rédigés à ce sujet, fort peu de recherches ont exploré le rôle des infirmières au niveau des soins et de la prise de décision en fin de vie.

De récentes études sur les soins en fin de vie suggèrent que des améliorations du processus de communication et de prise de décision pourraient rehausser la qualité des soins en fin de vie. SUPPORT, un acronyme qui correspond à Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments, est une étude d'envergure réalisée aux États-Unis dans 5 centres auprès de quelque 9000 patients. L'objectif de cette étude à deux phases était d'améliorer la prise de décision en fin de vie et de réduire la fréquence de processus du mourir à la fois pénibles et prolongés faisant appel à des aides mécaniques. La phase 1 consistait à décrire et à observer la prise de décision et les résultats pour les patients chez 4301 sujets. On a mis à jour des lacunes en matière de communication et des traitements de survie agressifs: seulement 47 % des médecins connaissaient les préférences de leurs patients, 46 % des directives Ne pas réanimer étaient émises dans les 48 heures précédant le décès, 38 % des patients avaient fait un séjour de 10 jours en unité de soins intensifs, et ils étaient nombreux à avoir éprouvé des douleurs allant de modérées à aiguës durant leurs derniers jours de vie. Les conclusions de la phase 1 suggèrent que la gestion des soins était surtout influencée par la piètre qualité de la communication médecin-patient. Quant à la phase 2, il s'agissait d'une intervention centrée sur les infirmières. Une infirmière compétente entretenait des rapports avec la famille, le patient et le médecin en vue de cerner les préférences, d'améliorer chez le patient et les proches la compréhension des



Helene Hudson, 1945-1993

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résultats pour le patient, d'encourager l'attention portée à la maîtrise de la douleur et de faciliter la planification préliminaire des soins et la communication. Cette étude faisait uniquement appel à une infirmière, en tant qu'agent de communication, de facilitation et de défense de l'intérêt du patient, en vue d'améliorer le processus de prise de décision. Aucune différence significative ne marquait les résultats cliniques ou économiques mesurés. L'échec apparent de cette intervention suggère qu'il existe d'autres déterminants plus importants dont la compréhension nous échappe encore.

Par conséquent, cette recherche avait deux buts précis: (1) déterminer auprès de patients gravement malades hospitalisés pour un cancer ou pour une autre maladie leur préférence en matière de rôle décisionnel portant sur la fin de vie; (2) déterminer si leurs soignants (infirmières et médecins) étaient au courant de leur préférence en matière de rôle. Nous avons émis l'hypothèse que les patients hospitalisés gravement malades préféreraient confier la responsabilité concernant les traitements de fin de vie aux professionnels qui leur prodiguent des soins ou bien la partager avec eux, et que les patients cancéreux et non cancéreux pourraient avoir des vécus différents puisque la trajectoire de la maladie est d'une nature plus prévisible dans le cas du cancer et que, au fil des ans, les patients atteints de cancer ont bénéficié d'une approche plus formelle en matière de planification préliminaire des soins et d'accès aux soins palliatifs. En second lieu, nous avons avancé l'hypothèse que la plupart des soignants ignoraient les préférences de leurs patients. Le but à long terme du groupe de travail End of Life Research Working Group (EOLRWG) est d'élaborer et d'évaluer des processus visant à améliorer la prise de décisions relatives à la fin de vie. Les prestataires des soins de santé (infirmières et médecins) sont des éléments essentiels du processus. En fin de ligne, l'amélioration des processus de prise de décision permettra de rehausser l'efficacité et la qualité des soins en fin de vie.

Recension des écrits

Prise de décision en fin de vie

Nous tenons notre compréhension actuelle de la prise de décision en fin de vie de conceptualisations publiées et des résultats empiriques d'études portant sur la prise de décision en matière de soins de santé, étudiée la plupart du temps chez d'autres populations de patients. Plusieurs facteurs influent sur le processus et/ou sur les résultats des décisions cliniques concernant les patients en fin de vie. Les facteurs intrapersonnels incluent les caractéristiques personnelles, physiques, psychologiques et socioculturelles de chaque patient comme l'état de santé, les préférences du patient, les problèmes pour lesquels des décisions doivent être prises, ses croyances et ses valeurs. Les facteurs interpersonnels sont ceux qui ont une incidence sur les interactions décisionnelles dans la réalité de tous les jours et sur le processus de partage de l'information, de délibération et enfin, sur la décision proprement dite. Les caractéristiques des soignants, notamment les connaissances et les compétences, les croyances et les valeurs, influenceront la nature et la portée de ces interactions. Celles-ci sont aussi influencées par la nature contextuelle du milieu dans lequel elles se produisent. Les discussions portant sur les soins en fin de vie pourront varier selon qu'elles se passent au domicile du patient ou dans un établissement de soins actifs.

La nature interactionnelle de la prise de décision thérapeutique en constitue à la fois une force et une faiblesse. Les interactions exigent de grandes quantités de temps et d'énergie et présupposent que les soignants et les patients sont prêts à s'investir dans le processus et que des options de traitement sont disponibles. Chaque interaction s'accompagne d'un processus de prise de décision. Charles et collaborateurs

(1997) ont défini trois rôles modèles et trois stades analytiques distincts à l'intérieur du processus de prise de décision: échange d'information, délibération sur les options de traitement et choix de l'option de traitement souhaitée. Ces processus varient d'une interaction patient-soignant à l'autre en fonction de la nature des rapports que ceux-ci entretiennent. Par échange d'information, on entend les types et la quantité d'information échangés. La quantité d'information et la direction dans laquelle elle circule varient selon le modèle retenu. Par exemple, si le patient se cantonne dans un rôle passif et si le soignant joue un rôle actif, la circulation de l'information se fait principalement à sens unique, du soignant au patient. Le soignant communique au patient le minimum d'information afin de satisfaire aux exigences du consentement éclairé. Dans le modèle privilégiant l'information du patient, celle-ci circule de nouveau du soignant au patient, mais cette fois, le soignant lui communique toute l'information qu'il souhaite avoir en vue de l'aider à prendre sa décision. Dans un modèle de prise de décision partagée, l'échange d'information est réciproque. Le soignant communique l'information éclairant la prise de décision tandis que le patient le renseigne sur ses valeurs, son style de vie, ses craintes et ses préférences. Le processus d'échange d'information s'avère parfois être un élément critique de la prise de décision en fin de vie.

Les recherches examinant le rôle préféré des patients hospitalisés gravement malades sont limitées. Le rôle perçu et désiré des patients en ce qui a trait au processus de prise de décision a fait l'objet de davantage d'études dans d'autres populations de patients, notamment chez les patients cancéreux traités en ambulatoire. En comparaison avec la population générale, les patients atteints de cancer préfèrent adopter un rôle plus passif dans le processus de prise de décision. Ces études portant sur le rôle préféré des patients sont instructives, mais elles ne peuvent pas nécessairement être généralisées en ce qui concerne les patients atteints du cancer ou d'une autre maladie qui doivent prendre des décisions thérapeutiques en fin de vie (par opposition à des décisions prises au sujet du traitement de leur cancer).

Cadre organisationnel pour la prise de décision en fin de vie

Nous nous sommes efforcées d'intégrer un bon nombre de concepts dans un cadre organisationnel en vue d'orienter cette étude (et d'autres) conduites par le End of Life Research Working Group (Heyland, Tranmer et Feldman-Stewart, 2000). Le cadre comprend quatre "unités d'étude": a) le soignant, b) le patient, c) le processus de prise de décision, d) le résultat pour le patient. Il convient de souligner ici qu'il s'agit d'un cadre organisationnel, et on ne dira jamais assez que, d'un point de vue conceptuel, la prise de décision est complexe, surtout en fin de vie. Les interactions sont continues, elles impliquent de nombreux soignants et proches, surviennent au sein d'un environnement social complexe souvent marqué par des priorités et des valeurs divergentes; enfin, les décisions, véritables reflets des valeurs, ont ici un caractère final. Bien que nous ayons conceptualisé trois modèles d'interactions patient-soignant (passif, coopératif, actif), ces modèles ne sont pas censés représenter des processus ou des événements rigides. Les patients et les soignants pourront changer de modèle d'une interaction à l'autre ou même dans le cadre d'une même interaction. Par exemple, un médecin assumant un rôle actif pourra reconnaître que son patient a besoin de recevoir davantage d'information et de participer plus activement à la prise de décision, et il pourra adopter un modèle de prise de décision partagée. Le ou les résultats optimaux pour le patient seront uniques pour chaque personne concernée, d'où la difficulté de les définir et de les mesurer.

Rôle des soins infirmiers dans la prise de décision en fin de vie

Si l'on conçoit les soins de santé et la prise de décision en fin de vie en tant que continuum, ayant à un bout le patient qui souhaite en assumer la pleine responsabilité et le contrôle, et, à l'autre bout, le médecin (le soignant) qui prescrit les décisions cliniques en matière de soins, nous formulons l'hypothèse que l'infirmière assume plusieurs rôles – facilitation, interprétation et clarification – et qu'elle joue souvent le rôle de «filtre» favorisant la communication entre le médecin et le patient. L'infirmière-médiatrice interprète pour le compte du médecin et défend les intérêts du patient et de la famille. Il en découle que si l'infirmière participe au processus en jouant un rôle médiateur au niveau des préférences du patient, sa perception du degré de responsabilité relative à la prise de décision par le patient doit correspondre à celle du patient.

Fort peu d'études de recherche se sont penchées sur le rôle de l'infirmière vis-à-vis des décisions relatives à la fin de vie, bien que quelques études aient examiné les attitudes infirmières face aux questions de fin de vie. Le processus de prise de décision présente des lacunes évidentes, et celles qui peuvent concerner les infirmières n'ont pas été résolues de manière satisfaisante. Une récente étude de Wilson et collègues (1997) visant à comparer la capacité des internes et celle des médecins traitants à prédire les choix que feraient leurs patients hospitalisés gravement malades relativement aux traitements en fin de vie a révélé que les médecins apprenaient souvent les préférences des patients en matière de RCR de sources autres que les patients eux-mêmes. Malheureusement, aucune donnée spécifique ne permettait de quantifier ce «souvent». Pas plus qu'on indiquait de quelles sources il s'agissait, bien qu'il soit possible d'envisager que l'infirmière du patient constituait l'une de ces sources principales. Une étude de Baggs (1993) a permis de découvrir que le degré de coopération entre infirmières et internes et résidents de l'unité de soins intensifs au niveau de la décision de faire sortir un patient de cette unité, tel que signalé par les infirmières, était un prédicteur statistiquement significatif du risque de résultat négatif pour le patient. À mesure que la coopération se développait, tel que signalée par les infirmières, l'incidence de résultats négatifs pour le patient diminuait. La coopération, telle que rapportée par les internes et les résidents, n'était pas associée, statistiquement, aux résultats pour le patient. Quoique cette étude n'ait pas analysé directement les décisions relatives à la fin de vie, ses résultats montrent que le rôle joué par les infirmières sur le plan de la prise de décision clinique peut avoir une incidence sur les résultats pour le patient.

La phase II de l'étude SUPPORT avait pour but d'améliorer la prise de décision en fin de vie et de réduire la fréquence des processus du mourir pénibles et prolongés faisant appel à la technologie. Dans cette étude sur échantillon aléatoire et contrôlé, des groupes de médecins recevaient ou non l'intervention sur une base randomisée. Cette intervention voyait les infirmières (1) fournir aux médecins des données pronostiques; (2) obtenir les préférences des patients; (3) encourager le médecin à privilégier la prise en charge de la douleur; (4) faciliter la planification préliminaire des soins; (5) faciliter la communication médecin-patient. Bien que l'étude SUPPORT n'ait pas réussi à atteindre une signification statistique pour les cinq résultats primaires – reconnaissance par le médecin des préférences du patient; incidence et moment de documentation des directives Ne pas réanimer; quantité de douleur éprouvée par les patients; durée des séjours en unité de soins intensifs, durée du coma ou du raccordement à un ventilateur mécanique avant le décès; utilisation des ressources hospitalières – on ne peut pas en conclure que les infirmières n'ont aucun rôle à jouer dans les décisions relatives à la fin de vie.

Dans une critique de l'étude SUPPORT, Oddi et Cassidy suggéraient que les piètres résultats pourraient trouver leur origine dans le faible entendement qu'avaient les chercheurs de la compétence et des connaissances infirmières, et, par la suite, de leur intégration à la conception du projet et à l'intervention. On demandait aux infirmières d'élaborer leur rôle de manière autonome, sur le modèle des «infirmières spécialisées». Les critères de sélection des infirmières, leur antécédents en éducation, leur préparation et leurs responsabilités variaient d'un centre à l'autre. L'échec des infirmières à titre de communicatrices tient peut-être au fait que leur information n'était pas valorisée ou ne paraissait pas crédible. Les infirmières ont peut-être échoué dans le rôle de défense de l'intérêt des patients parce qu'elles manquaient d'affirmation de soi et qu'elles n'avaient pas l'appui de l'équipe de soins. Elles étaient prises entre deux feux: d'un côté les patients et leurs proches et de l'autre, les médecins – les signes de coopération étant plutôt rares. Toutefois, Oliverio et Fraulo (1998) ont émis des commentaires favorables sur le rôle des infirmières cliniciennes. Ils déclaraient qu'ils avaient réussi à saisir la complexité et les craintes des patients et des proches tout au long de ce processus, et que c'est peut-être dans cette complexité qu'il fallait trouver les raisons de l'échec apparent des efforts de communication. Ils affirmaient qu'il incombe aux infirmières de faire en sorte que les soins soient prodigués en fonction des préférences des patients et des proches, mais aussi en considération du jugement clinique de l'équipe de santé. Le rôle des infirmières consistait à donner du sens à des facteurs complexes comme la technologie de pointe, l'espoir, la futilité et le fardeau de la prise de décision. Ils suggéraient également qu'il serait plus pertinent de mesurer les résultats liés au processus, au confort des patients et au «caring».

Résumé

Pour les patients gravement malades, hospitalisés pour un cancer ou pour une autre maladie, la prise de décision en fin de vie est complexe. De récentes recherches suggèrent que les efforts fournis en vue d'améliorer les soins en fin de vie n'ont pas porté fruit. Et que, notamment, le rôle des soins infirmiers fait encore l'objet d'un sous-développement et d'une sous-utilisation. Cette étude avait donc pour but d'explorer, dans la perspective des patients et dans celle des soignants, des aspects importants de la prise de décision en fin de vie chez les patients gravement malades hospitalisés pour un cancer ou pour une autre maladie.

Questions posées dans le cadre de l'étude

Cette étude était axée sur trois questions de recherche:

1. Quel rôle les patients hospitalisés gravement malades souhaitent-ils adopter dans les décisions relatives aux traitements de survie?
2. Y a-t-il une différence en matière de préférences relatives au rôle décisionnel chez les patients diagnostiqués d'un cancer et les autres?
3. Les soignants (infirmières et médecins) connaissent-ils les préférences des patients en matière de rôle décisionnel, et dans l'affirmative, quelle concordance leurs connaissances entretiennent-elles avec la réalité?

Méthodologie de la recherche

La conception retenue pour l'étude était celle d'une enquête transversale axée sur des cas particuliers qui a pris la forme d'entretiens individuels. L'étude a été réalisée dans un hôpital de soins actifs associé à une université du sud-est de l'Ontario. La population visée par l'étude comprenait les patients admis au Kingston General Hospital qui répondaient aux critères d'inclusion des patients, les infirmières responsables de ces patients ainsi que leur médecin traitant et les médecins résidents concernés.

Les critères d'inclusion des patients exigeaient de ceux-ci qu'ils aient au moins dix-huit ans, aient été admis à l'hôpital pour des raisons médicales et aient au moins une des comorbidités suivantes: (a) broncho-pneumopathie chronique obstructive (BPCO) déterminée par la présence d'au moins deux des éléments suivants: pression de CO₂ de référence \geq 45 torr, cœur pulmonaire, insuffisance respiratoire dans les 12 derniers mois ou volume expiratoire maximal de \leq 25 %; (b) insuffisance cardiaque globale (ICG) déterminée selon les symptômes de la classe IV de la New York Heart Association pour la fonction ventriculaire \leq 25 %; (c) cirrhose déterminée par imagerie diagnostique ou varices œsophagiennes et coma hépatique ou maladie du foie de classe B ou C, ou (d) cancer métastatique (avec complication); patients dont le séjour à l'hôpital devait durer au moins 72 heures et capables de s'exprimer en anglais. On a exclu de l'étude les patients souffrant de troubles psychiatriques, ceux chez qui on supposait des difficultés de communication (obstacles linguistiques, culturels ou cognitifs) et ceux qui faisaient face à une mort imminente. Les critères d'inclusion des patients retenus pour l'échantillon de l'étude reflétaient les critères d'inclusion utilisés dans l'étude SUPPORT. L'échantillon comprenait les patients dont l'état pouvait se détériorer à un tel point qu'il leur faudrait peut-être faire face à des décisions de fin de vie, et dont la probabilité de survie à 6 mois était de l'ordre de 50 %.

On a communiqué avec l'infirmière responsable de chaque sujet et avec le médecin traitant et le médecin résident attiré de ce dernier afin de les inviter à participer à l'étude. Par infirmière responsable, on entend l'infirmière ayant la responsabilité du patient le jour de l'entretien. Le médecin traitant était le médecin membre du personnel qui était responsable des soins médicaux dispensés à l'hôpital au moment de la réalisation de l'enquête auprès du patient. Quant au résident responsable, il s'agissait du résident senior chargé des soins au patient.

Mesures

Nous avons obtenu les données auprès des patients au moyen d'un questionnaire structuré administré par une assistante de recherche. Le questionnaire se composait d'un préambule expliquant les objectifs de l'étude, de questions visant à déterminer le rôle du patient dans la prise de décisions, de questions visant à déterminer avec qui le patient se sent à l'aise pour discuter de questions de fin de vie et d'une section servant à recueillir des données démographiques. Nous n'avons pas utilisé l'approche du classement de fiches conçue par Degner et Sloan (1992) car nous nous inquiétions du temps qu'exigerait le classement des réponses et voulions aussi utiliser la même méthodologie avec les médecins et les infirmières. L'instrument de mesure retenu pour les médecins et les infirmières comportait un sous-ensemble de questions tirées du questionnaire administré aux patients. Le questionnaire visant les soignants évaluait la perception du médecin et de l'infirmière à propos du rôle que le patient aimerait adopter relativement aux décisions de fin de vie. En outre, les patients et les soignants avaient la possibilité de commenter leurs réponses.

Collecte des données

On a informé tous les médecins traitants au sujet de l'étude et on a recherché leur appui quant à la participation des patients dont les soins étaient sous leur responsabilité. La plupart des médecins traitants ont accepté d'y participer. Un nombre restreint de médecins se préoccupait du sujet de l'étude, à savoir les questions entourant la fin de vie, particulièrement dans le cas des patients avec qui ils n'avaient pas abordé ces questions. Nous nous sommes efforcés de rassurer les médecins en leur expliquant que nous explorions le processus de prise de décision pour tenter d'en décrire les forces et les lacunes et que nous nous intéressions aux préférences en matière de rôle décisionnel et non pas aux préférences en matière de soins.

On communiquait avec les patients en vue de solliciter leur participation s'ils satisfaisaient aux critères d'inclusion et étaient à l'hôpital depuis au moins trois jours. Une fois le consentement du patient obtenu, l'assistante de recherche effectuait l'entretien. L'infirmière responsable du patient le jour de l'entrevue, le médecin résident senior chargé des responsabilités majeures et le médecin traitant recevaient un questionnaire à compléter pour chaque patient participant à l'étude. Le protocole de recherche a été examiné et approuvé par le Kingston Health Sciences Research Ethic Board [Comité d'éthique pour la recherche].

Résultats

Échantillon

Le recrutement des patients a démarré en juillet 1999 et celui des soignants en février 2000 et il continuera pendant les six prochains mois. En juillet 2000, soit la date du présent rapport, le taux de participation des patients s'élevait à 57 % (122/215). La raison la plus fréquente de non participation était le souhait chez les patients de ne pas faire partie d'une étude. Le taux de réponse/participation chez les infirmières, résidents et médecins traitants était, respectivement, de l'ordre de 86 % (46/53), de 64 % (19/29) et de 77 % (26/34). Pour les besoins du présent rapport, on a amalgamé les réponses des médecins traitants et des résidents en une seule catégorie, celle des médecins.

Caractéristique	n	Cancéreux	n	Non cancéreux
Genre	56		61	
Féminin		30 (54 %)		27 (44 %)
Masculin		26 (46 %)		34 (56 %)
Âge moyen	56	66 (écart-type 12)	61	(72 écart-type 18)
Décédé dans les 6 mois suivants l'entretien*	43	74 % (32)	37	54 % (20)
Séjour en unité de soins intensifs	56	4 (7 %)	61	18 (30 %)
Discussions sur la fin de vie documentées	56	17 (30 %)	61	20 (33 %)
Directive de soins en fin de vie documentées	56	20 (36 %)	61	20 (33 %)
Consultation en soins palliatifs	56	24 (43 %)	61	3 (5 %)
Éducation	52		54	
Études sec. non terminées		17 (33 %)		22 (41 %)
Études sec. terminées		14 (27 %)		16 (30 %)
Études post-secondaires		21 (41 %)		16 (30 %)
Conditions de logement	52		54	
Vit seul(e)		10 (19 %)		17 (31 %)
Vit avec des proches		38 (73 %)		33 (60 %)
Logement protégé		4 (9 %)		4 (9 %)

* Les données ne sont disponibles que pour les patients recrutés durant les 6 premiers mois ou pour ceux qui sont décédés avant juillet 2000.

Caractéristiques des patients

Les résultats concernent les 117 premiers patients recrutés pour l'étude (voir le tableau 1). Il s'agit de personnes âgées. Parmi les patients recrutés au cours des six premiers mois de l'étude, 74 % des sujets atteints de cancer et 54 % des sujets souffrant d'autres affections étaient décédés. Un nombre plus important de patients atteints de BPCO et d'insuffisance cardiaque globale avaient été admis en unité de soins intensifs par rapport aux patients atteints de cancer. Ces derniers étaient plus nombreux à avoir bénéficié de consultations relatives aux soins palliatifs. Cependant, c'est seulement pour un tiers des patients des deux groupes que les notes au dossier indiquaient des discussions sur les soins en fin de vie ou une directive en la matière. La majorité des patients vivaient seuls ou avec un proche. Dans cet échantillon, 58 % (62/107) étaient mariés, 26 % (28/107) divorcés et le reste, soit 15 % (17/107), étaient soit célibataires soit veufs. La plupart étaient à la retraite (81 %, 87/107).

Caractéristiques des infirmières

Les infirmières (n=42) travaillaient au sein d'unités de médecine et de chirurgie. Vingt-neuf pour cent occupaient des postes à temps partiel, 60 % des postes à temps plein et le restant, 11 %, des postes temporaires à temps partiel ou à temps plein. Les infirmières de cet échantillon travaillaient en moyenne depuis 11 ans et leur expérience en milieu de travail s'étendait de 1 mois à 33 années. Dans cet établissement, l'attribution des patients se fait au gré des quarts de travail, et il n'y a donc pas d'attribution d'infirmière de soins intégraux. Une seule infirmière clinicienne spécialisée en soins palliatifs fournit un support important aux patients et aux familles.

Discussions relatives à la fin de vie

Dans la première partie de l'entrevue, on posait aux patients les questions présentées dans le tableau 2. La plupart des patients (77 %,

Questions	n	Cancéreux	n	Non cancéreux
Avez-vous réfléchi aux types de traitements que vous aimeriez recevoir si vous développiez une complication virtuellement mortelle?	56	43 (77 %)	60	46 (77 %)
Durant ce séjour à l'hôpital, avez-vous discuté de vos souhaits avec votre médecin?	56	21 (38 %)	60	22 (37 %)
• Si non, seriez-vous prêt(e) à discuter de vos souhaits avec votre médecin?	35	25 (71 %)	32	26 (82 %)
Durant ce séjour à l'hôpital, avez-vous discuté de vos souhaits avec votre infirmière ou d'autres professionnels de la santé?	56	7 (13 %)	60	11 (18 %)
• Si non, seriez-vous prêt(e) à discuter de vos souhaits avec d'autres professionnels de la santé?	49	31 (63 %)	49	30 (61 %)
Existe-t-il quelque part une version écrite ou sonore de vos souhaits?	56	31 (55 %)	60	35 (58 %)

89/116) avaient déjà réfléchi aux traitements qu'ils aimeraient recevoir s'ils développaient une complication mettant leur vie en danger. Cependant, comme l'indiquent les dossiers des bénéficiaires, ils n'étaient que 37 % (n=43/116) à signaler de telles discussions. La plupart d'entre eux étaient prêts à aborder de telles questions avec leur médecin. Les patients qui ne voulaient pas parler des soins en fin de vie déclaraient qu'ils aborderaient ces questions avec d'autres personnes (p. ex. le médecin de famille) ou ils estimaient qu'ils n'avaient pas besoin d'en discuter à ce moment-là. Les patients rapportaient peu de discussions sur les soins en fin de vie avec les infirmières ou d'autres soignants professionnels (n=18, 16 %). En revanche, ils étaient nombreux à exprimer le désir d'en parler avec des infirmières. Plus de la moitié des patients de l'échantillon signalaient qu'ils avaient des directives préalables sous une forme ou sous une autre – habituellement conservées ailleurs qu'à l'hôpital (n=66, 57 %).

Préférence en matière de rôle décisionnel

Dans cet échantillon, il n'y avait aucune différence entre les patients atteints de cancer et ceux atteints d'autres maladies en ce qui concerne le désir de jouer un rôle décisionnel (voir le tableau 3). Les préférences variaient à ce sujet. La majorité des patients exprimaient le désir de jouer un rôle partagé ou un rôle plus actif dans la prise de décisions relatives aux traitements de survie. Les patients ont émis des commentaires éclairés sur leurs points de vue. Un patient ayant exprimé le désir de jouer un rôle partagé a déclaré:

Les patients préfèrent :	Cancéreux (n=50)	Non cancéreux (n=57)
Confier à leur médecin la responsabilité des décisions	5 (10 %)	7 (12 %)
Demander au médecin de prendre les décisions finales après avoir fait un examen sérieux de leur opinion	4 (8 %)	6 (11 %)
Partager la responsabilité décisionnelle avec le médecin	16 (32 %)	21 (37 %)
Prendre eux-mêmes les décisions finales après avoir fait un examen sérieux de l'opinion du médecin	17 (34 %)	13 (23 %)
Prendre eux-mêmes les décisions	8 (16 %)	10 (18 %)
Préférences des patients quant au rôle des proches:		
Confier à leur médecin la responsabilité des décisions	5 (10 %)	9 (16 %)
Demander au médecin de prendre les décisions finales après avoir fait un examen sérieux de leur opinion	1 (2 %)	7 (12 %)
Partager la responsabilité décisionnelle avec le médecin	19 (38 %)	17 (29 %)
Prendre eux-mêmes les décisions finales après avoir fait un examen sérieux de l'opinion du médecin	19 (38 %)	15 (26 %)
Prendre eux-mêmes les décisions	6 (12 %)	9 (16 %)

Cela a plus de sens – il faut que j'en discute avec le médecin puisqu'il sait quels sont les traitements qui me conviendraient le mieux. C'est un professionnel des soins, il pourrait me dire quelle est la meilleure option, et je respecterais son opinion.

Une patiente qui exprimait le désir d'adopter un rôle plus actif nous confiait: «Il s'agit de mon corps, et la décision me revient. Je veux exercer un contrôle – la vie et le mourir dépendent de la volonté de l'individu.» Les patients étaient moins nombreux, mais un nombre substantiel tout de même, à souhaiter que le médecin assume un rôle plus marqué. Ils s'exprimaient en ces termes: «Je ne suis pas docteur – je suis incapable de prendre cette décision – il doit savoir ce qu'il fait.» Nous avons également demandé aux patients quel rôle ils aimeraient que leurs proches jouent s'ils étaient eux-mêmes dans l'incapacité de prendre part aux décisions. On a noté les mêmes tendances dans les réponses.

Perception des préférences des patients chez les soignants

Les réponses proposées aux soignants étaient similaires à celles proposées aux patients (voir le tableau 4). Par contre, les soignants pouvaient indiquer qu'il leur était impossible de déterminer les préférences de leurs patients. Quarante-six pour cent des infirmières de l'échantillon signalaient qu'elles ne connaissaient pas suffisamment bien les patients pour déterminer leurs préférences en matière de rôle décisionnel relatif aux décisions de soins en fin de vie. Les médecins étaient moins nombreux à signaler ce manque de perception, mais comme ils étaient moins nombreux que les infirmières à participer à l'étude, on pourrait assimiler ce manque de participation au manque de perception. Les infirmières ajoutaient des commentaires du genre: «on vient juste de m'attribuer la responsabilité de ce patient», «elles jugeaient ne pas connaître suffisamment bien le patient pour

aborder ces questions», «que l'état du patient s'était stabilisé et qu'il n'y avait aucun besoin de discuter de ces questions-là». Les médecins déclaraient également que l'état du patient était actuellement stable et qu'ils n'avaient donc pas besoin de mentionner les soins en fin de vie. Dans certains cas, ils ne connaissaient pas suffisamment bien les patients – c.-à-d. qu'ils remplaçaient des collègues oncologues auprès des patients hospitalisés.

On a analysé le degré de correspondance entre la préférence de chaque patient et la perception de l'infirmière. On notait un rôle actif si les patients ou les soignants indiquaient que le patient souhaitait prendre la décision avec ou sans l'avis du médecin, un rôle coopératif correspondant à la prise de décision partagée, tandis qu'un rôle passif allait de pair avec les catégories pour lesquelles les patients déclaraient qu'ils voulaient que ce soit le médecin qui décide de par lui-même ou après s'être enquis de leur opinion. Cette ventilation par catégories est semblable à la catégorisation mise au point par Degner et Sloan (1992) après avoir cerné les préférences grâce à la technique de tri des fiches. Les réponses des infirmières correspondaient à celles des patients dans 19 % des cas; toutefois, lorsque les infirmières évaluaient les préférences des patients, la concordance s'élevait à 38 % (8/21). Les patients rapportaient une préférence plus marquée pour le rôle actif par rapport au rôle passif. Cependant, la différence réelle était minime (une différence de l'ordre de 1).

La plupart des infirmières (95 %, n=44) et 36 % (n=16) des médecins signalaient qu'ils n'avaient pas abordé les traitements de survie auprès des patients. Vingt-trois pour cent des médecins (n=10) ont déclaré avoir discuté des traitements de survie avec les patients, affirmation confirmée par les patients. Une proportion importante de médecins (30 %, n=13) rapportaient s'en être entretenus avec les patients alors que ces derniers affirmaient que non, ou que, au contraire, le médecin avançait qu'il n'y avait eu aucune discussion à ce sujet alors que les patients contredisaient leurs propos. Si l'on considère cet échantillon de patients dans son ensemble, on note la rareté des communications axées sur les traitements en fin de vie.

Résumé des conclusions

Les patients en fin de vie adoptent des préférences différentes en matière de rôle décisionnel, mais la majorité (80 %, n=80) préfèrent un processus de partage et une participation active dans la prise de décision. On ne remarquait aucune différence en matière de rôle décisionnel chez les patients ayant reçu un diagnostic primaire de cancer par rapport aux patients dont le diagnostic primaire était associé à une autre maladie. Les infirmières (et les médecins) œuvrant dans ce milieu de soins actifs ignoraient les préférences des patients en matière de rôle décisionnel ou les interprétaient incorrectement. Des thèmes communs sont apparus: le patient n'était pas en phase critique, on venait de se voir attribuer la responsabilité du patient, ambiguïté des rôles et absence de processus de communication.

Forces et limitations de l'étude

La principale force de cette étude est que l'échantillon est le reflet exact des patients qui sont parvenus au stade de la fin de vie puisque plus de 50 % des patients recrutés au cours des six premiers mois sont décédés depuis. La deuxième force de cette étude réside dans son utilisation de groupes de référence. Dans bien des hôpitaux, les patients atteints de cancer ont souvent, lors de leur admission, des complications liées directement ou indirectement à leur cancer ou à d'autres affections sous-jacentes. Il importait donc de déterminer les similitudes et les différences entre les patients hospitalisés gravement malades. Enfin, cette étude reflète le monde réel des soignants et les influences contextuelles au sein d'un hôpital d'enseignement des soins tertiaires, notamment la multiplicité des attributions patients-soignants.

Table 4: Perception des préférences des patients par les soignants

Ce patient préfère:	Infirmière (n=46)	Médecin (n=45)
Confier au médecin la responsabilité des décisions	1 (2 %)	3 (7 %)
Demander au médecin de prendre les décisions finales après avoir fait un examen sérieux de leur opinion	3 (7 %)	3 (7 %)
Décider ensemble	7 (15 %)	14 (31 %)
Prendre la décision tout en tenant compte de l'opinion du médecin	12 (26 %)	19 (42 %)
Prendre ses propres décisions	2 (4 %)	2 (4 %)
Ne sait pas	21 (46 %)	4 (9 %)
Convergence patient-soignant:	Dyade infirmière-patient (n=42)	Dyade médecin-patient (n=45)
Le patient et le soignant choisissent la même préférence en matière de rôle	8 (19 %)	9 (21 %)
Le patient souhaite jouer un rôle plus actif que celui retenu par le soignant	8 (19 %)	17 (40 %)
Le patient souhaite jouer un rôle plus passif que celui retenu par le soignant	5 (12 %)	13 (30 %)
Le soignant n'est pas à même de déterminer la préférence	21 (50 %)	4 (12 %)

La limitation majeure de cette étude réside dans l'emploi d'une enquête transversale pour mesurer un processus aussi complexe que la prise de décision. Nous avons privilégié certains aspects (p. ex. le rôle décisionnel) de la prise de décision à un moment précis. Bien que nous ayons pu dégager des conclusions importantes, de nouvelles études longitudinales pourraient explorer l'incidence de déterminants importants d'une prise de décision efficace en fin de vie. D'ailleurs, les assistantes de recherche ont souvent fait des commentaires à propos de la "richesse" de certains des entretiens effectués. Enfin, l'échantillon des soignants est de taille restreinte. La collecte des données se poursuivra jusqu'à ce qu'on possède un échantillon suffisant pour généraliser les conclusions.

Discussion

Les conclusions de cette étude révèlent que, au sein de l'échantillon de patients hospitalisés gravement malades, la plupart ont réfléchi aux traitements en fin de vie et qu'ils sont prêts à en discuter avec les médecins et les infirmières, et qu'en dépit de cela, ils sont peu nombreux à avoir eu l'occasion de le faire. Les infirmières ne se sentaient pas à l'aise pour aborder ces questions car elles estimaient que cela faisait partie du rôle du médecin et qu'on venait à peine de leur assigner les patients. Les médecins déclaraient souvent que la tâche revenait à «quelqu'un d'autre» ou que l'état du patient n'était pas assez critique pour la justifier. Les écrits de recherche rapportent des inquiétudes quant au caractère tardif ou inapproprié des discussions relatives à la fin de vie, notamment l'aiguillage vers les soins palliatifs ou l'introduction de directives de fin de vie. Les conclusions de cette étude confirment ces préoccupations. Malheureusement, la plupart des patients ayant les conditions et les critères diagnostiques retenus pour cette étude sont décédés en moins de six mois. Les soignants ne savent pas s'il s'agit de l'hospitalisation qui peut s'avérer être la toute dernière du patient – nous devrions donc engager les discussions à propos de la fin de vie avant le passage à la phase critique où la douleur ou les symptômes deviennent impossibles à maîtriser ou que la mort ne devienne inévitable. Nous n'ignorons pas les critères pronostiques et les patients (et leur famille) sont d'accord pour qu'on aborde le sujet, mais, en vertu de la culture du milieu des soins actifs, on attend qu'une crise survienne pour agir. Il faut donc que l'on parle de la question des soins en fin de vie avant que les patients ne soient sur le point d'expirer.

Les préférences des patients variaient d'un patient à l'autre en ce qui concerne le rôle décisionnel, mais ils étaient nombreux à exprimer le désir de participer d'une façon quelconque à l'échange d'information et à la délibération, et d'assumer la responsabilité décisionnelle. Ce n'est pas la conclusion à laquelle nous nous attendions car nous avions émis l'hypothèse que les patients, du fait de la gravité de leur maladie, se déchargeraient de cette responsabilité sur les soignants. Nous avançons deux explications possibles pour cette conclusion. Tout d'abord, la décision de mettre un point final à la vie est "un enjeu de taille", et il est fort probable que les patients (et les proches) savent exactement la manière dont ils voudraient que cette phase de la vie se passe. Ils veulent participer au processus et avoir droit au chapitre. Pourquoi les patients choisissent-ils un rôle passif de leur plein gré? Est-ce là leur souhait véritable ou une réaction à leurs sentiments de vulnérabilité et de perte de contrôle ou, réciproquement, cela tient-il à la saine confiance qu'ils ont dans les décisions prises par les médecins et d'autres professionnels? Cela ne semble pas lié à la gravité de leur maladie ou à leur mort inévitable. Ensuite, les patients réalisent peut-être qu'il n'ont pas vraiment d'options – c'est soit la vie, soit la mort. Ce qui n'est pas le cas des autres décisions de nature médicale ou sanitaire. De plus, bon nombre des patients étaient atteints d'affections chroniques, et ils étaient parfaitement au courant de leurs propres conditions et vécu. Ils étaient capables de prendre une décision éclairée.

La majorité des infirmières de notre échantillon ignoraient les préférences des patients ou les interprétaient de façon incorrecte.

En nous fondant sur les déclarations de principes et énoncés de politiques de notre profession, nous supposons que l'infirmière jouerait un rôle de clarification, de défense des intérêts des patients et de médiation pour le compte de ces derniers en ce qui a trait aux décisions relatives aux soins en fin de vie; pourtant, les résultats de notre étude indiquent que ce n'est pas le cas dans le milieu des soins actifs. Dans ce centre hospitalier, les infirmières se voient assigner les patients au fil de leurs quarts de travail, et la communication portant sur les besoins des patients et les soins de santé est souvent axée sur les besoins immédiats – le recours aux quarts de travail n'accorde que peu d'importance à la discussion proactive des questions entourant les soins de santé qui ne se rapportent pas directement aux besoins immédiats – et cette méthode de distribution du travail donne peu d'occasions de le faire. Cependant, de nombreux hôpitaux font appel à une gamme de stratégies pour essayer de combler quelques-unes des lacunes – visites cliniques en vue du congé, spécialistes en soins palliatifs et planification préliminaire des soins. Malheureusement, comme le montrent les résultats de notre étude, peu de patients en bénéficient (p. ex. peu de consultations en soins palliatifs au profit des patients cancéreux et aucune en faveur des patients souffrant d'autres maladies) ou alors dans les tout derniers moments de vie. Il est inquiétant que certaines infirmières abandonnent au médecin l'entière responsabilité des discussions portant sur les soins en fin de vie. Car les infirmières ont un rôle et un mandat professionnels à ce sujet, et les administrateurs professionnels de centres hospitaliers et autres doivent fournir aux infirmières le soutien nécessaire pour prodiguer ces soins. Oliverio et Fraulo (1998) ont offert plusieurs suggestions en se basant sur l'expérience acquise dans le cadre de l'étude SUPPORT. Ils recommandaient (a) que l'on voie dans la mort un phénomène naturel inévitable; (b) que les discussions portant sur les questions relatives aux soins en fin de vie surviennent plus tôt dans tous les contextes de soins et que leur communication soit rigoureuse; (c) que les infirmières prennent conscience du fardeau que représente pour les proches la participation aux décisions relatives à la fin de vie et qu'elles interviennent afin de l'alléger; (d) qu'il faut considérer la création de cultures (et peut-être même d'unités) visant à appuyer les soins en fin de vie; (e) qu'il faut rassurer les patients en leur disant qu'ils recevront des soins de qualité peu importe leurs préférences décisionnelles. Ils recommandaient également la mise en œuvre, dans les hôpitaux, d'un rôle semblable à celui de l'infirmière SUPPORT. Nous recommandons l'élaboration et l'évaluation de stratégies polyvalentes en vue d'améliorer les soins en fin de vie. On pourrait notamment accroître la sensibilisation sur les questions entourant la fin de vie; améliorer les connaissances et les compétences du personnel infirmier se rapportant aux questions de qualité des soins en fin de vie; appuyer les infirmières lorsqu'elles défendent les intérêts des patients et leur fournir des mentors à cet effet; établir des méthodes de communication qui soient fiables et réalisables; mettre en œuvre des méthodes permettant aux soignants et aux patients, s'ils le désirent, de discuter de décisions importantes concernant les soins.

De tous temps, les infirmières ont fourni des soins empreints de compassion aux mourants et à leur famille. Nous nous devons d'étendre l'administration de ce genre de soins aux patients approchant la fin de vie. Les patients sont prêts à s'impliquer. Les infirmières du milieu des soins actifs doivent intégrer les processus de soins en fin de vie au répertoire de connaissances et de soins spécialisés qu'elles prodiguent habituellement aux patients hospitalisés gravement malades. Le défi pour les infirmières (et pour les médecins) est de prodiguer ces soins dans le contexte des soins actifs qui privilégie les traitements et se caractérise par son évolution constante et sa complexité.

La bibliographie se trouve à la page 13.

The utilization and efficiency of the informal caregivers' coping strategies

By Gemma Aucoin-Gallant

Abstract

This study highlights the coping strategies used by informal caregivers whose husbands live with cancer. It also aims at measuring the efficiency of the selected strategies. The convenience sample was composed of 30 informal caregivers. The results indicate that informal caregivers primarily use support, optimism, independence, and facing of the situation. In general, the categories of coping strategies most often used by informal caregivers are considered by them to be the most efficient. The results of the study encourage nurses to identify more regularly the coping strategies used by informal caregivers; to recognize their efficiency and implement interventions likely to improve the informal caregivers' stress management.

In the current health care context, people with cancer remain in their natural environment as much as possible (Adams, 1991; Fitzgerald, 1999). Even though these patients may benefit from some community-based support services, the fact remains that women bear important responsibilities in the care they provide to their husbands. These women are referred to as informal caregivers (Garand & Bolduc, 1990). While performing their familial, professional, and social functions, women must deal with their informal caregiver roles (Aucoin, 1998). The coping process takes place in the context of this unusual situation. Coping refers to the person's ability to deal with a stressful situation (Fitzgerald). Coping strategies include what informal caregivers think and do when faced with a stressful situation. Thus, the wives develop strategies to come to terms with their feelings and try to overcome an unexpected situation.

The vast majority of studies conducted with informal caregivers show that they need to receive psychological support (Aucoin, 1998). The published literature offers very little information on the strategies used by informal caregivers whose husbands have cancer. Also, no study assessed the efficiency of the coping strategies used by this population. For Lazarus and Folkman (1984), coping strategies are efficient as long as they help the person reduce or manage their stress. The purpose of this investigation was to describe the coping strategies used by informal caregivers, and to also assess the efficiency of the chosen strategies in order to understand the spousal experience throughout this stressful situation. With an improved knowledge of the coping strategies used by informal caregivers, nurses can initiate and implement interventions likely to help the informal caregivers manage their stress.

Investigation purpose and questions

The purpose of this study was to describe the coping strategies used by informal caregivers whose husbands are living with cancer. It also assessed the efficiency of the coping strategies used by this population. The research questions were as follows:

1. What are the coping strategies used by informal caregivers whose husbands are living with cancer?
2. Do informal caregivers use more problem-focused coping strategies than emotion-focused ones?
3. What coping strategies are rated as most efficient by informal caregivers whose husbands have cancer?

Conceptual framework

The conceptual framework created by Lazarus and Folkman (1984) provided the theoretical foundation for this study. According to Lazarus and Folkman, coping represents the sum of strategies a person adopts in order to deal with life's stressful situations. In their work, Lazarus and Folkman consider coping strategies as the cognitive and behavioural efforts produced by an individual to react to the demands of his or her environment that are seen as exceeding his or her current resources. Lazarus and Folkman believe that the person assesses the significance of the stressor in relation to his or her well-being. First an assessment is made as to whether the event is irrelevant, harmless, positive, or stressful. During this primary evaluation, the person determines the presence or absence of stress. If the event is perceived in a stressful way, it may be seen as a loss, a threat, or a challenge. Perceptions of loss or threat usually generate anxiety, fear, and concern. As for challenge, it may represent a gain for the person or at least an opportunity to adequately manage the stressful situation.

Then the person assesses the resources and available options to deal with the event, as well as those which are best suited to the situation. The person also reassesses the event. This new evaluation is based on new signs emanating from the environment and on the strategies used to deal with the situation. Lazarus and Folkman specify that for a given event reassessing helps to understand the efficiency of the interaction between the selected coping strategies and the environment. In their publications, they describe two main types of coping strategies: emotion-focused and problem-focused. Generally speaking, emotion-focused coping strategies are more likely to be used if the person believes that nothing can change his or her current situation. On the other hand, if the person thinks that the stressful conditions may be modified, it is very likely that their coping strategies will be focused around the problem (Lazarus & Folkman). These authors indicate that the two types of coping strategies are usually used simultaneously.

Methodology

This descriptive study was conducted with 30 informal caregivers whose husbands had been living with cancer for six to 12 months, either in stable condition or undergoing chemotherapy or radiation treatment. The sample was chosen through convenience sampling. The subjects were free to participate or not in the study and they signed a consent form. Data collection took place at the residences of the informal caregivers at times convenient to them. The data were gathered via a single at-home interview which lasted 40 minutes on average. A socio-demographic data form and the Jalowiec Coping Scale (1987) were used. Killeen (1990) and Gulick (1995) report that Jalowiec's instrument is consistent with Lazarus and Folkman's coping theory (1984). According to these authors, the opinions of Jalowiec and Lazarus and Folkman are similar as they indicate the same two main types of coping strategies: one focused on emotions

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and one centred on the problem. The researcher observes that the Jalowiec Coping Scale is the only instrument that measures the efficiency of the coping strategies used by the subjects. The instrument's internal consistency was measured using Cronbach's alpha co-efficients of 0.88 for identifying coping strategies and 0.81 for their efficiency.

Findings

The first research question was phrased as follows: "What are the coping strategies used by informal caregivers whose husbands are living with cancer?" To get an answer to this question, informal caregivers were invited to indicate on a scale of 0 to 3 the level of use for each of the 60 coping strategies listed in Jalowiec's instrument (1987). Table One illustrates the means and standard deviations for the eight categories of coping strategies. Based on the informal caregivers' perceptions, the three categories of most frequently used strategies were the following: support (M=2.61), optimism (M=2.51) and independence (M=2.11). One should note that the use level for each of these coping strategies ranges from "never used" (0) to "often used" (3). "Expression of emotions" (M=1.17) "avoidance" (M=1.09) and "fatalism" (M=0.67) are the three categories of coping strategies informal caregivers use the least. As one can see in Table One, coping strategy categories are of two types: problem-focused and emotion-focused.

In addition to identifying the categories of coping strategies used the most by the subjects, it is necessary to describe those most frequently used at the time of data collection. Informal caregivers choose to talk about their problem with family members or their friends. It is the most commonly used coping strategy to deal with their current situation and it belongs to the support category. According to informal caregivers, talking about their situation, about cancer for example, provides mutual support to family members and assists them in overcoming the event. Informal caregivers try to keep their situation under control, lead as normal a life as possible, and maintain positive thoughts. By resorting to these three strategies, informal caregivers rely on their support and demonstrate their ability to face the situation and show optimism. Informal caregivers are hoping things will improve and entertain positive thoughts. Table Two illustrates the 10 coping strategies most often used by informal caregivers whose husbands have cancer. It also indicates the categories to which each of these coping strategies belongs. For example, praying and counting on others for help belong to the support category.

The second research question asked: "Do informal caregivers use more problem-focused coping strategies than emotion-focused ones?". Student's t-test was used to answer this question. The means

were calculated for both groups. The sample yielded a significant difference between the use of problem-focused and emotion-focused coping strategies. It was found that informal caregivers rely more on problem-focused strategies relative to emotion-focused ones.

The third research question read thus: "What coping strategies are rated as most efficient by informal caregivers whose husbands have cancer?" To answer this question, informal caregivers indicated, on a scale of 0 to 3, the level of efficiency for each of the coping strategies they used. Table Three presents means and standard deviations for the efficiency of the eight categories of coping strategies. The results show that support, optimism, and facing the situation are the three most efficient categories of coping strategies for the research subjects. On the other hand, avoidance, expression of emotions and fatalism are the three categories perceived as the most inefficient by informal caregivers. It is interesting to note that informal caregivers rated problem-focused strategies as efficient. Overall, the categories of coping strategies most often used by informal caregivers were also perceived by them as the most efficient.

Interpretation of data

The results of our study indicate that informal caregivers use both strategies focusing on the problem and those focusing on emotions. This recourse to both types of strategies was mentioned in the work of Lazarus and Folkman (1984) and that of Killeen (1990). In this study, informal caregivers drew on a variety of coping strategies, which may lead one to suppose they are going through a stressful situation. It is worth remembering that coping logically succeeds stress. After having assessed the situation as stressful, the caregivers use coping strategies to lessen or manage their stress. Even though informal caregivers are living through a difficult situation, those who rely on different forms of coping strategies are at a lesser risk of developing emotional vulnerability (Miller, 1990). Thus they are demonstrating flexibility in their coping process (Lazarus & Folkman).

Support is the coping strategy category that informal caregivers utilize the most. They share their concerns and anxieties with relatives and friends. By opening up to others and revealing their feelings, they reduce tension and create solidarity that promotes a state of

Table One: Utilization of coping strategy categories by informal caregivers: Means

N = 30

Classification of coping strategy categories	Mean	Utilization Standard Deviation
1. Support*	2.61	0.28
2. Optimism**	2.51	0.16
3. Independence**	2.11	0.23
4. Facing the situation*	2.02	0.19
5. Palliative coping**	1.51	0.26
6. Expression of emotions**	1.17	0.21
7. Avoidance**	1.09	0.17
8. Fatalism**	0.67	0.22

* Problem-focused coping strategy category

** Emotion-focused coping strategy category

Possible scores ranged from 0 to 3.

Table Two: The 10 most frequently used coping strategies among informal caregivers

N=30

Rank	Strategy	Category
First	You discussed your problem with your family or your friends	Support*
Second	You tried to keep the situation under control	Facing*
Third	You maintained as normal a life as possible by not letting the problem intimidate you	Optimism**
Fourth	You tried entertaining positive thoughts	Optimism**
Fifth	You wished for things to get better	Optimism**
Sixth	You remembered how you had solved other problems in the past	Independence**
Seventh	You prayed and put your trust in God	Support *
Eighth	You counted on others to help you	Support *
Ninth	You tried to control your emotions	Independence**
Tenth	You worried about the problem	Expression of emotions**

* Problem-focused coping strategy category

** Emotion-focused coping strategy category

The coping scale is composed of 60 strategies

psychological wellness (Weisman, 1977). In case of need, informal caregivers can also count on a reliable and accessible social network. To mitigate tensions linked to the disease, Lieberman (1982) believes that accessibility is a more important notion than the actual use of the resources offered by the social network. In the literature related to this topic, a consensus seems to emerge that the coping strategy of support is often used and is efficient in helping people deal with the disease-related sources of stress (Jalowiec, 1993).

The results confirm that informal caregivers display an optimistic attitude in the face of their stressful situation. In this instance, they appear resistant to pessimistic ideas regarding their spouses' disease. Being and remaining optimistic when faced with a disease were reported by Jalowiec (1993). Concentrating on the positive side of the situation promotes the acceptance of the disease by restructuring the experience to give it meaning (Watson, 1985). Patterson (1989) mentions that people who remain optimistic in the face of a stressful situation demonstrate an open mind, active engagement, and the use of a variety of coping strategies. Lazarus and Folkman (1984) believe that the use of optimistic strategies may facilitate the subsequent use of problem-focused strategies.

Among the groups of coping strategies used by the subjects, independence came in third place. It is evident that informal caregivers rely on past experiences to better deal with their situation. This finding reflects the work of Lazarus and Folkman (1984) who stated that adults draw from their past experience to better come to grips with the problems of everyday life. Thus, the adult experience represents a valuable resource in the use of coping strategies (Lazarus, 1991). The study shows that informal caregivers make an effort to manage their feelings. Controlling one's emotions is interpreted by Jalowiec (1993) as a way of maintaining one's independence in the face of a difficult situation linked to a disease.

It is interesting to note that informal caregivers use more problem-focused strategies than emotion-focused ones. According to Lazarus and Folkman (1984), problem-focused coping strategies are more frequently used in stressful situations related to work. However, when dealing with a chronic health problem, people think they cannot change the source of stress. Therefore they tend to choose emotion-focused strategies. Beaulieu (1993) stresses that people use more problem-focused coping strategies when a stressful situation involves a task to be completed. In the investigation, informal caregivers cared for spouses with cancer. This indeed is a task to be performed. It is likely that caring for one's husband becomes a priority as a stressful situation when compared to the cancer itself. Even though the nature of the event, e.g. disease or work, has an impact on the coping strategies, one should not conclude that it is the only influencing factor.

When it comes to the efficiency of coping strategies, it is worth remembering that the subjects were assessed selectively, i.e. through a single interview. However, one can group these strategies as being of a high efficiency, medium efficiency, or low efficiency. In the study, the most efficient strategy categories are support, optimism, and facing of the situation. These results are close to those reported by Weisman (1977) who thinks that the person who endeavours to objectively examine a problem tends to be more successful in the analysis. This gives meaning to the event and incorporates it gradually into everyday life. Then the person seeks out positive elements from the situation. The individual calls upon the support of family members, friends, and their own religious beliefs. Still according to Weisman, these strategies are the most efficient to adapt to a stressful situation related to cancer.

According to the study subjects, independence and positive compensation strategies, referred to as positive palliative coping, are considered as being of medium efficiency. Jalowiec (1993) emphasizes that, by controlling their emotions and relying on their previous experience, people can be more independent in their actions. While positive compensation strategies, such as diversion, are not problem-centred, this type of strategy promotes emotion control (Lazarus & Folkman, 1984). For Jalowiec, independence and positive palliative coping are considered to be adequately efficient by people experiencing stress linked to a disease.

Avoidance, expression of emotions and fatalism are among the strategies that informal caregivers rated as less efficient. These results agree with the ideas put forward by Weisman (1977). This author concludes that people who deny reality, who blame others and who, through fatalism, resign themselves to the situation, are using non-efficient strategies to cope with a situation related to cancer. However, Lazarus and Folkman (1984) think that temporary denial may be valuable at the onset of the disease. At that time, people have few resources available to them to focus their strategies on the problem. Denial allows them to diminish their emotional reaction to the situation.

Conclusion

This study demonstrates that informal caregivers adopt problem-focused coping strategies more frequently as opposed to emotion-focused ones. It emphasizes that informal caregivers use mostly support, optimism, independence, and facing of the situation. It may well be that the support and optimism together allow informal caregivers to better deal with the situation. It is interesting to observe that, in general, the categories of coping most often used by informal caregivers are also viewed by them as being the most efficient. Nowadays, in the early part of 2001, nurses should be able to implement an evaluation and reinforcement process for coping strategies. This will allow them to identify the coping strategies being used, to recognize their level of efficiency, and to develop interventions aimed at helping the caregivers to better manage their stress.

This investigation's limitations are worth mentioning. The study utilized a convenience sample. Therefore, the results are limited to the sample under consideration and their generalization is impossible. Coping strategies were assessed on an ad hoc basis, i.e. through a single interview. As coping constitutes a process, the identified strategies have a rather limited scope. One can wonder if most of the coping strategies vary significantly over time. Longitudinal studies with adults experiencing stressful situations related to cancer would help paint a more comprehensive picture of their usual coping strategies. Other studies could analyze the nature of the relationships between optimism, support, and facing the situation. Correlational studies could explore the relationships between a stressful event, the socio-demographic variables in adults, and the use of coping strategies.

References are found on page 27.

Table Three: Efficiency of coping strategy categories used by informal caregivers: Means

N = 30

Classification of coping strategy categories	Efficiency	
	Mean	Standard deviation
1. Support*	2.72	0.21
2. Optimism**	2.53	0.12
3. Independence**	2.43	0.21
4. Facing the situation*	2.13	0.28
5. Palliative coping**	2.11	0.22
6. Expression of emotions**	1.43	0.21
7. Avoidance**	0.73	0.23
8. Fatalism**	0.67	0.21

* Problem-focused coping strategy category

** Emotion-focused coping strategy category

To obtain the means for the utilization of coping strategies, the rank was 0 to 3.

L'utilisation et l'efficacité des stratégies de «coping» de la soignante naturelle

par Gemma Aucoin-Gallant

L'abrégé

Cette étude fait ressortir les stratégies de «coping» utilisées par la soignante naturelle dont le conjoint est atteint de cancer. Elle mesure aussi l'efficacité des stratégies choisies. L'échantillon de convenance est composé de 30 soignantes naturelles. Les résultats obtenus démontrent que les soignantes naturelles utilisent surtout le soutien, l'optimisme, l'indépendance, et l'affrontement de la situation. Dans l'ensemble, les catégories des stratégies de «coping» les plus utilisées par les soignantes naturelles sont considérées, par celles-ci, comme les plus efficaces. Les résultats obtenus incitent les infirmières à identifier davantage les stratégies de «coping» utilisées par la soignante naturelle; reconnaître leur efficacité et mettre sur pied des interventions susceptibles de l'aider à mieux gérer son stress.

Dans le contexte actuel des soins de santé, la personne atteinte de cancer est maintenue le plus possible dans son milieu naturel (Adams, 1991; Fitzgerald, 1999). Bien que cette personne malade puisse bénéficier de quelques services de soutien offerts dans la communauté, il reste que la femme assume des responsabilités importantes dans les soins qu'elle donne à son conjoint. Cette personne est appelée soignante naturelle (Garand & Bolduc, 1990). Tout en s'acquittant de ses fonctions familiales, professionnelles, et sociales, l'épouse est confrontée à son rôle de soignante naturelle (Aucoin, 1998). Dans cette situation inhabituelle, le processus de «coping» prend place. Le «coping» signifie la capacité de la personne de faire face à une situation jugée stressante (Fitzgerald). Les stratégies de «coping» regroupent ce que la soignante naturelle pense et ce qu'elle fait lors d'une situation jugée stressante. Ainsi, l'épouse développe des stratégies pour assumer ses émotions et tenter de surmonter cette situation inattendue.

La grande majorité des études effectuées auprès des soignantes naturelles mettent en évidence que la soignante

naturelle a besoin d'être soutenue psychologiquement (Aucoin, 1998). À travers les écrits, il existe toutefois très peu d'information sur les stratégies utilisées par la soignante naturelle dont le conjoint est atteint de cancer. Également, aucune étude n'a vérifié l'efficacité des stratégies de «coping» utilisées par cette population. Selon Lazarus et Folkman (1984), les stratégies de «coping» sont efficaces dans la mesure où elles aident la personne à diminuer ou à gérer le stress. Cette recherche s'intéresse à décrire les stratégies de «coping» utilisées par la soignante naturelle et à vérifier également l'efficacité des stratégies choisies afin de mieux saisir ce que vit la conjointe en situation de stress. En connaissant mieux les stratégies de «coping» que la soignante naturelle utilise, les infirmières peuvent initier et mettre en route des interventions susceptibles de l'aider à mieux gérer son stress.

Le but et les questions de l'étude

Cette étude a pour but de décrire les stratégies de «coping» de la soignante naturelle dont le conjoint est atteint de cancer. Elle vérifie également l'efficacité des stratégies de «coping» utilisées par cette population. Les questions de recherche retenues sont les suivantes:

1. Quelles sont les stratégies de «coping» utilisées par la soignante naturelle dont le conjoint est atteint de cancer?
2. Est-ce que les soignantes naturelles utilisent davantage les stratégies de «coping» axées sur le problème en comparaison avec les stratégies de «coping» centrées sur les émotions?
3. Quelles sont les stratégies de «coping» jugées les plus efficaces par la soignante naturelle dont le conjoint est atteint de cancer?

Le cadre conceptuel

Le cadre conceptuel proposé par Lazarus et Folkman (1984) sert d'assise théorique à cette recherche. Selon Lazarus et Folkman (1984), le «coping» représente l'ensemble des stratégies que la personne adopte afin de faire face aux différentes situations stressantes de la vie. Dans leurs écrits, Lazarus et Folkman considèrent les stratégies de «coping» comme des efforts cognitifs et comportementaux fournis par l'individu en vue de réagir aux demandes de son environnement qui sont évaluées comme excédant les ressources actuelles de la personne. De l'avis de Lazarus et Folkman, la personne évalue la signification de l'agent stressant par rapport à son état de bien-être. Elle juge d'abord si l'événement en question est pour elle sans pertinence, bénin, positif ou stressant. Lors de cette évaluation primaire, la personne détermine la présence ou l'absence de stress. Si l'événement est perçu de manière stressante, il peut être considéré comme une perte, une menace, ou un défi. Les perceptions de perte ou de menace génèrent habituellement de l'inquiétude, de la peur, et de la préoccupation. Quant au défi, il peut représenter un gain pour la personne ou tout au moins la possibilité de gérer adéquatement la situation stressante.

La personne évalue ensuite les ressources et les options disponibles pour faire face à l'événement de même que celles qui seraient les meilleures dans sa situation. La personne fait aussi une nouvelle évaluation de l'événement. Cette réévaluation est basée sur de nouveaux signes provenant de son environnement et sur les stratégies utilisées pour faire face à la situation. Lazarus et Folkman (1984) spécifient que, par rapport à un événement, la réévaluation permet de connaître l'efficacité de l'interaction entre les stratégies de «coping» choisies et l'environnement.

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Dans leurs écrits, Lazarus et Folkman décrivent deux types principaux de stratégies de «coping»: celui centré sur les émotions et celui axé sur le problème. De façon générale, les stratégies de «coping» centrées sur les émotions ont plus tendance à être utilisées si la personne évalue que rien ne peut changer sa situation actuelle. Par contre, si la personne évalue qu'il est possible de modifier les conditions stressantes, il est fort probable que ses stratégies de «coping» seront axées sur le problème (Lazarus & Folkman). Ces deux auteurs affirment que les deux types de stratégies de «coping» sont habituellement utilisés simultanément.

La méthode

Cette recherche descriptive a été menée auprès de 30 soignantes naturelles dont le conjoint est atteint d'un cancer depuis 6 à 12 mois, en phase de stabilisation et sous traitement de chimiothérapie ou de radiothérapie. L'échantillon de convenance a été privilégié. Les sujets étaient libres de participer à l'étude et ont signé un formulaire de consentement. La collecte des données a eu lieu au domicile de la soignante naturelle au moment qui lui convenait. Les données ont été recueillies par le biais d'une seule entrevue à domicile d'une durée moyenne de 40 minutes. Un formulaire de données sociodémographiques et l'échelle de «coping» de Jalowiec (1987) ont été utilisés. Killeen (1990) et Gulick (1995) précisent que l'instrument de Jalowiec est consistant avec la théorie de «coping» de Lazarus et Folkman (1984). Selon ces auteurs, les points de vue de Jalowiec et ceux de Lazarus et Folkman se ressemblent puisqu'ils précisent les deux mêmes types principaux de stratégies de «coping»: celui centré sur les émotions et celui axé sur le problème. La chercheuse constate que l'échelle de «coping» de Jalowiec est le seul instrument qui mesure l'efficacité des stratégies de «coping» utilisées par les sujets. La consistance interne de l'instrument est mesurée à l'aide d'un alpha de Cronbach à 0,88 en ce qui concerne l'identification des stratégies de «coping» et à 0,81 pour l'efficacité de celles-ci.

Les résultats

La première question de recherche s'énonce comme suit. Quelles sont les stratégies de «coping» utilisées par la soignante naturelle dont le conjoint est atteint de cancer? Afin d'obtenir une réponse à cette question, les soignantes naturelles ont été invitées à indiquer sur un échelle de 0 à 3, le degré d'utilisation de chacune des 60 stratégies de «coping» énumérées dans l'instrument de Jalowiec (1987). Le tableau 1 présente les moyennes et les écarts types de l'utilisation des huit catégories de stratégies de «coping». Selon la perception des soignantes naturelles, les trois catégories de stratégies les plus utilisées sont les suivantes: le soutien ($M=2,61$), l'optimisme ($M=2,51$) et l'indépendance ($M=2,11$). Il est à noter que le degré d'utilisation de chacune des stratégies de «coping» se situe entre jamais utilisée (0) et souvent utilisée (3). L'expression des émotions ($M=1,17$) l'évitement ($M=1,09$) et le fatalisme ($M=0,67$) sont les trois catégories de stratégies de «coping» les moins utilisées par les soignantes naturelles. On voit au tableau 1, que les catégories de stratégies de «coping» se regroupent en deux types : celui axé sur le problème et celui centré sur les émotions.

En plus d'identifier les catégories de stratégies de «coping» les plus utilisées par les sujets, il importe de décrire les stratégies les plus utilisées au moment de la collecte des données. Les soignantes naturelles choisissent de parler de leur problème avec leur famille ou leurs ami(e)s. C'est la stratégie de «coping» la plus utilisée pour faire face à leur situation actuelle et celle-ci se retrouve dans la catégorie intitulée soutien. Selon les soignantes naturelles, parler de leur situation, par exemple du cancer, amène

les membres de la famille à se soutenir mutuellement et à mieux surmonter l'événement. Les soignantes naturelles essaient de maintenir leur situation sous contrôle, d'avoir une vie aussi normale que possible, et d'entretenir des pensées positives. En employant ces trois stratégies, les soignantes naturelles s'appuient sur le soutien et elles montrent l'affrontement de la situation et l'optimisme. Les soignantes naturelles souhaitent que les choses s'améliorent et elles font preuve de pensée positive. Le tableau 2 illustre les dix stratégies de «coping» les plus utilisées par les soignantes naturelles dont le conjoint est atteint de cancer. Ce tableau précise aussi les catégories dans lesquelles se retrouvent chacune des stratégies de «coping» les plus utilisées par les sujets. À titre d'exemple, prier et compter sur les autres pour vous aider font partie de la catégorie nommée soutien.

La deuxième question de recherche se lit ainsi: Est-ce que les soignantes naturelles utilisent davantage des stratégies de «coping» axées sur le problème en comparaison avec les stratégies centrées sur les émotions? Le test bilatéral t de Student a été utilisé pour répondre à cette question. Le calcul des moyennes des deux groupes a été effectué. Dans notre échantillon, il existe une différence significative entre l'utilisation des stratégies de «coping» axées sur le problème et celles centrées sur les émotions. Il ressort que les soignantes naturelles utilisent davantage les stratégies axées sur le problème comparativement aux stratégies centrées sur les émotions.

La troisième question de recherche est la suivante: Quelles sont les stratégies de «coping» jugées les plus efficaces par la soignante naturelle dont le conjoint est atteint de cancer? Afin de répondre à cette question, les soignantes naturelles ont indiqué sur une échelle de 0 à 3, le degré d'efficacité de chacune des stratégies de «coping» qu'elles utilisaient. Le tableau 3 précise les moyennes et les écarts types de l'efficacité des huit catégories de stratégies de «coping». Les résultats obtenus montrent que le soutien, l'optimisme, et l'affrontement de la situation sont les trois catégories de stratégies de «coping» les plus efficaces pour les sujets de l'étude. Par contre, l'évitement, l'expression des émotions, et le fatalisme sont les trois catégories de stratégies jugées les plus inefficaces par les soignantes naturelles. Il est intéressant de remarquer que les soignantes naturelles ont considéré comme efficaces les stratégies centrées sur le problème. Dans l'ensemble, les catégories de stratégies de «coping» les plus utilisées par les soignantes naturelles sont considérées, par celles-ci, comme les plus efficaces.

L'interprétation des données

Les résultats de notre étude démontrent que les soignantes naturelles utilisent les stratégies axées sur le problème et celles centrées sur les émotions. Cette façon d'avoir recours aux stratégies orientées vers le problème et à celles axées sur les émotions a été rapportée dans les écrits de Lazarus et Folkman (1984) ainsi que ceux de Killeen (1990). Dans notre étude, les soignantes naturelles adoptent une variété de stratégies de «coping», ce qui peut laisser présumer qu'elles vivent une situation stressante. Rappelons que le «coping» fait suite, de façon logique, au stress. Après que la soignante naturelle ait évalué la situation comme stressante, elle utilise des stratégies de «coping» pour diminuer ou gérer la tension. Même si les soignantes naturelles vivent une situation difficile, celles qui ont recours à des formes variées de stratégies de «coping» risquent moins de développer de la vulnérabilité émotionnelle (Miller, 1990). Elles démontrent donc une flexibilité dans leur processus de «coping» (Lazarus & Folkman).

Le soutien est la catégorie de stratégies de «coping» la plus utilisée par les soignantes naturelles. Celles-ci partagent leurs préoccupations et leurs inquiétudes avec les membres de la

famille et des amis. S'ouvrir aux autres et dévoiler ses sentiments diminuent la tension et créent une solidarité favorisant un état de mieux-être psychologique (Weisman, 1977). En cas de besoin, les soignantes naturelles peuvent aussi compter sur un réseau social accessible et fiable. Pour atténuer les tensions liées à la maladie, Lieberman (1982) croit que l'accessibilité est une notion plus importante que le fait d'utiliser les ressources du réseau social. Dans la littérature traitant du sujet, il se dégage un consensus à savoir que le soutien est une catégorie de stratégie de «coping» souvent utilisée et efficace pour aider les personnes à faire face aux sources de stress liées à la maladie (Jalowiec, 1993).

Les résultats obtenus confirment que les soignantes naturelles affichent une attitude optimiste à l'égard de leur situation stressante. En l'occurrence, elles apparaissent réfractaires aux idées pessimistes concernant la maladie de leur conjoint. Le fait d'être et de demeurer optimiste devant une situation de maladie a été rapporté par Jalowiec (1993). Se concentrer sur le positif de la situation favorise l'acceptation de la maladie en restructurant l'expérience vécue pour y trouver un sens (Watson, 1985). Patterson (1989) mentionne que la personne optimiste à l'égard d'une situation stressante fait preuve d'ouverture d'esprit, d'implication active, et qu'elle utilise une diversité de stratégies de «coping». Lazarus et Folkman (1984) croient qu'avoir recours à des stratégies dites optimistes peut faciliter l'usage subséquent de stratégies axées sur le problème.

Parmi les groupes de stratégies de «coping» utilisées par les sujets, l'indépendance occupe le troisième rang. Il appert que les soignantes naturelles s'appuient sur les expériences passées pour mieux faire face à leur situation. Cette donnée correspond aux écrits de Lazarus et Folkman (1984) concernant le fait que l'adulte se base sur son expérience passée pour mieux composer avec les problèmes de la vie quotidienne. Ainsi, l'expérience de l'adulte constitue une ressource précieuse dans l'utilisation des stratégies de «coping» (Lazarus, 1991). D'après notre étude, les soignantes naturelles font des efforts pour maîtriser leurs émotions. Contrôler les émotions est d'ailleurs interprété par Jalowiec (1993) comme une façon de maintenir l'indépendance devant une situation difficile liée à la maladie.

Il est intéressant de constater que les soignantes naturelles utilisent davantage des stratégies axées sur le problème comparativement aux stratégies centrées sur les émotions. Selon Lazarus et Folkman (1984), les stratégies de «coping» centrées

sur le problème sont plus utilisées dans des situations stressantes liées au travail. Par contre, lorsqu'il s'agit d'un problème de santé chronique, la personne estime n'avoir aucune possibilité de changer la source de stress. Elle choisit donc plus des stratégies centrées sur les émotions. Pour sa part, Beaulieu (1993) souligne que les personnes utilisent davantage des stratégies de «coping» axées sur le problème lorsque la situation stressante implique un travail à faire. Dans notre recherche, les soignantes naturelles prennent soin de leur conjoint atteint de cancer. Il s'agit là d'une tâche à accomplir. Il est probable que donner des soins au conjoint devienne prioritaire en tant que situation stressante en comparaison avec le phénomène du cancer lui-même. Bien que la nature de l'événement, par exemple la maladie ou le travail, influence les stratégies de «coping», il ne faut pas en conclure que ce soit le seul facteur d'influence.

En ce qui concerne l'efficacité des stratégies de «coping», rappelons que les sujets l'ont évaluée de manière ponctuelle, c'est-à-dire par le biais d'une seule entrevue. Il est néanmoins possible de les regrouper selon qu'elles sont plus efficaces, moyennement efficaces, ou peu efficaces. Dans cette étude, les catégories de stratégies les plus efficaces sont le soutien, l'optimisme, et l'affrontement de la situation. Ces résultats se rapprochent de ceux rapportés par Weisman (1977). Selon cet auteur, la personne qui entreprend d'examiner objectivement le problème réussit mieux à l'analyser. Elle donne un sens à l'événement et l'intègre progressivement dans sa vie quotidienne. Cette personne recherche alors des éléments positifs découlant de la situation. Elle a recours au soutien de sa famille et de ses amis, et a des croyances religieuses. Toujours selon Weisman, ces

Tableau 1 : Moyenne obtenue pour l'utilisation des catégories de stratégies de «coping» chez la soignante naturelle

N = 30

Classification des catégories de stratégies de «coping»	Utilisation	
	Moyenne	Écart-type
1. Soutien*	2,61	0,28
2. Optimisme**	2,51	0,16
3. Indépendance**	2,11	0,23
4. Affrontement de la situation*	2,02	0,19
5. «Coping» palliatif**	1,51	0,26
6. Expression des émotions**	1,17	0,21
7. Évitement**	1,09	0,17
8. Fatalisme**	0,67	0,22

* Cette catégorie des stratégies de «coping» est centrée sur le problème

** Cette catégorie des stratégies de «coping» est axée sur les émotions

Le rang pour l'obtention de la moyenne se situe entre 0 et 3 en ce qui concerne l'utilisation des stratégies de «coping».

Tableau 2 : Dix stratégies de «coping» les plus utilisées par les soignantes naturelles

N=30

Rang	Stratégie	Catégorie
Premier	Vous parliez de votre problème avec votre famille ou vos ami(e)s	Soutien*
Deuxième	Vous essayiez de maintenir la situation sous contrôle	Affrontement*
Troisième	Vous mainteniez une vie aussi normale que possible en ne vous laissant pas intimider par le problème	Optimisme**
Quatrième	Vous essayiez d'entretenir des pensées positives	Optimisme**
Cinquième	Vous souhaitiez que les choses s'améliorent	Optimisme**
Sixième	Vous vous souveniez comment vous avez résolu d'autres problèmes par le passé	Indépendance**
Septième	Vous priiez et mettiez votre confiance en Dieu	Soutien*
Huitième	Vous comptiez sur les autres pour vous aider	Soutien*
Neuvième	Vous essayiez de maîtriser vos émotions	Indépendance**
Dixième	Vous vous faisiez du souci au sujet du problème	Expression des émotions**

* Cette catégorie des stratégies de «coping» est centrée sur le problème

** Cette catégorie des stratégies de «coping» est axée sur les émotions

L'échelle de «coping» comprend 60 stratégies

stratégies sont les plus efficaces pour s'adapter à une situation stressante liée au cancer.

D'après les sujets de l'étude, l'indépendance et les stratégies de compensation positive intitulées le «coping» palliatif positif sont considérés comme ayant une efficacité moyenne. Jalowiec (1993) rappelle que maîtriser ses émotions et s'appuyer sur son expérience antérieure permet à la personne d'être plus indépendante dans ses actions. Même si les stratégies de compensation positive, telle la distraction, ne sont pas centrées sur le problème, il reste que ce type de stratégie favorise la maîtrise des émotions (Lazarus et Folkman, 1984). Selon Jalowiec, l'indépendance et le «coping» palliatif positif sont considérés comme passablement efficaces par les personnes soumises à des sources de stress liées à la maladie.

L'évitement, l'expression des émotions et le fatalisme font partie des stratégies qualifiées de peu efficaces par les soignantes naturelles. Ces données rejoignent les idées émises par Weisman (1977). Cet auteur conclut que la personne qui nie la réalité, qui blâme les autres et qui se résigne à la situation avec fatalisme, utilise alors des stratégies non efficaces pour s'adapter à une situation liée au cancer. Cependant, Lazarus et Folkman (1984) pensent que le déni temporaire peut être valable au début de la maladie. À ce moment-là, la personne dispose de peu de ressources pour concentrer ses stratégies sur le problème. Le déni lui permet donc de réduire sa réaction émotionnelle face à la situation.

La conclusion

Cette recherche démontre que les soignantes naturelles ont davantage recours aux stratégies de «coping» axées sur le problème comparativement aux stratégies centrées sur les émotions. Il ressort que les soignantes naturelles utilisent surtout le soutien, l'optimisme, l'indépendance, et l'affrontement de la situation. Il se peut que l'effet du soutien et de l'optimisme réunis amène la soignante naturelle à affronter davantage la situation. Il est intéressant d'observer que dans l'ensemble les catégories de «coping» les plus utilisées par les soignantes naturelles sont considérées, par celles-ci, comme les plus efficaces. Au début de l'an 2001, l'infirmière doit être capable de mettre en route un processus d'évaluation et de renforcement pour ce qui est des stratégies de «coping». Elle pourra ainsi identifier les stratégies de «coping» utilisées, reconnaître leur degré d'efficacité, et

mettre sur pied des interventions susceptibles d'aider la personne à mieux gérer son stress.

Cette recherche présente des limites qu'il importe de souligner. Dans cette étude, l'échantillon de convenance a été privilégié. Les résultats obtenus se limitent à l'échantillon étudié et la généralisation s'avère impossible. Les stratégies de «coping» ont été évaluées de manière ponctuelle, c'est-à-dire par le biais d'une seule entrevue. Comme le «coping» est un processus, les stratégies identifiées ont une portée plutôt limitative. On se demande si la plupart des stratégies de «coping» varient de manière significative dans le temps. Des recherches longitudinales auprès des adultes vivant des situations stressantes liées au cancer permettraient de tracer un portrait plus complet des stratégies habituelles de «coping». D'autres études pourraient examiner la nature des relations entre l'optimisme, le soutien, et l'affrontement de la situation. Des études corrélationnelles pourraient explorer les relations entre l'événement stressant, les variables sociodémographiques de l'adulte, et l'utilisation des stratégies de «coping».

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Tableau 3 : Moyenne obtenue pour l'efficacité des catégories de stratégies de «coping» chez la soignante naturelle

N = 30

Classification des catégories de stratégies de «coping»	Efficacité	
	Moyenne	Écart-type
1. Soutien*	2,72	0,21
2. Optimisme**	2,53	0,12
3. Indépendance**	2,43	0,21
4. Affrontement de la situation*	2,13	0,28
5. «Coping» palliatif**	2,11	0,22
6. Expression des émotions**	1,43	0,21
7. Évitement**	0,73	0,23
8. Fatalisme**	0,67	0,21

*Cette catégorie des stratégies de «coping» est centrée sur le problème

**Cette catégorie des stratégies de «coping» est axée sur les émotions

Le rang pour l'obtention de la moyenne se situe entre 0 et 3 en ce qui concerne l'utilisation des stratégies de «coping».

Linking nursing pain assessment, decision-making and documentation

By Carolyn Tayler and Barbara McLeod

Abstract

A clinical nurse specialist's (CNS) experience in the development and implementation of a pain assessment and treatment flowsheet (PATF) to enhance the nursing assessment, decision-making, and documentation of pain on a palliative care unit in a community hospital is described in this article. Members of the palliative care interdisciplinary team use the PATF for clinical decision-making in the day-to-day management of patients' pain. The PATF is undergoing revision and re-implementation to promote the utilization of the tool beyond the specialty of palliative care and into the general patient population.

A prerequisite to the effective treatment of pain is appropriate assessment (Vallerand, 1997). A serious challenge that nurses face in caring for patients experiencing pain is to make sure that

pain is accurately assessed and consistently documented in a timely manner.

The authors believe that by linking pain assessment and documentation on a pain assessment and treatment flowsheet (PATF), nurses are able to make more appropriate and effective nursing decisions about pain management in accordance with the patient's identified comfort goal or acceptable level of pain. Appropriate nursing decision-making based on current pain management research may support nurses in meeting their professional standards of nursing practice as they relate to pain management in clinical practice (Ferrell, Eberts, McCaffery, & Grant, 1991). However, as McCaffery and Ferrell (1999) found, nurses have become more informed about pain assessment and relief, yet too many nurses still lack the basic knowledge necessary to manage pain appropriately.

A Master's-prepared clinical nurse specialist (CNS) in palliative care was responsible for the development and implementation of the PATF on a palliative care unit in 1994. This tool, along with supporting guidelines for use, became the nursing standard of practice for pain assessment and documentation on the palliative care unit. Every three years, each nursing standard is routinely reviewed by Nursing Practice Council in accordance with specific criteria to ensure that the nursing standard is both current and meeting community standards of practice. An interesting finding of the PATF's standard review process in 1998 revealed that the PATF remained unchanged in clinical practice following its initial introduction. In addition, no continuous quality improvement initiatives were undertaken, nor was an outcome-based evaluation done with the PATF. There was a significant gap in nursing practice because no mechanisms were established for monitoring the outcomes of patient care related to pain management using the PATF. Consequently, only anecdotal evidence existed regarding the nurses' actual effectiveness in managing pain while using the PATF. As a first step towards outcome measures, the clinical resource nurse (CRN) in surgery/medicine worked with the palliative care staff to revise the tool. The process of initial development and revision is documented in this paper.

ABRÉGÉ: VERS L'INTÉGRATION, SELON UNE PERSPECTIVE INFIRMIÈRE, DE L'ÉVALUATION DE LA DOULEUR ET DE LA PRISE DE DÉCISIONS ET DE LA DOCUMENTATION CONNEXES

Cet article décrit l'expérience d'une infirmière clinicienne spécialisée en matière de développement et de mise en œuvre d'un bilan d'évaluation et de traitement de la douleur en vue d'améliorer, selon une perspective infirmière, l'évaluation de la douleur, la prise de décisions et la documentation connexes dans un service de soins palliatifs d'un hôpital communautaire. Les membres de l'équipe interdisciplinaire de soins palliatifs utilisent ce bilan pour prendre des décisions de nature clinique dans le cadre de la gestion quotidienne de la douleur chez les patients. Le bilan d'évaluation et de traitement de la douleur fait actuellement l'objet d'une révision et d'une nouvelle mise en œuvre afin de promouvoir l'emploi de cet outil en dehors de la spécialité des soins palliatifs et donc dans la population hospitalière générale.



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Literature review

Three central themes were identified in the literature during the review and revision process of the PATF: the slowness of organizations to incorporate pain assessments into the routine care of patients (Gaston-Johansson & Fall-Dickson, 1995); the inadequacy of poorly documented pain assessments (Carr, 1997); and the paucity of tools such as pain flow records and pain rating scales to guide clinical decision-making in practice (Barnason, Merboth, Pozehl, & Tietjen, 1998).

Pain is regarded as a subjective phenomenon. For example, the Agency for Health Care Policy and Research (AHCPR) states that "the single most reliable indicator of the existence and intensity of pain and any resultant distress is the patient's self-report" (Acute Pain Management Guideline Panel, 1992, p.6). Therefore, various pain assessment tools focus on the subjective nature of pain and the importance of self-report. However, the choice of tools used depends on the purpose of the assessment (baseline versus ongoing), patient setting and patient characteristics, treatments used, and, finally, issues related to time, feasibility, and relevance (Groenwald, Frogge, Goodman, & Yarbrow, 1997).

It was also noted that a shift in focus from pain relief to pain management evolved as an outcome of several developments. These developments included the expansion of knowledge about the psychology of pain; the creation of new diagnostic and treatment modalities, such as patient controlled analgesia; and the involvement of many different specialists in pain research and new services for the treatment of chronic pain (Benoliel, 1995).

Some researchers have begun to document the use of pain management tools in practice. For example, Ferrell, Wisdom, Rhiner, and Alletto (1991) described a simple one-page audit tool that measured whether or not objective pain ratings were used, and if the pain assessment reflected what medications were used. Sources of data included admission notes, care plan, RN notes, and MD notes. The audit tool also noted if there was evidence of follow-up evaluations. Ferrell, Wisdom et al.'s pain audit tool (PAT) was developed based on a review of the literature and the authors' clinical experiences. It was validated after extensive use by experts throughout the USA.

The purpose of this article is to describe the development, implementation, and revising of one specific pain assessment and documentation tool to support nursing decision-making in clinical practice. While it is recognized that once pain assessment and documentation tools have been integrated into practice, it is crucial to use a formal evaluation process to determine the effectiveness of the tools in assisting the team to provide comprehensive pain management, no formal evaluation of the tool has yet been undertaken.

Identified need for the PATF

The original development of the PATF took place in 1994 to enhance the care of patients on a 16-bed palliative care unit which offered intensive symptom management, respite, and end-of-life care. The nursing staff were experienced registered nurses and were supported by an interdisciplinary team. The majority of patients had lung or breast cancer and were typically admitted for management of uncontrolled pain or terminal/hospice care.

The CNS observed that the nurses consistently assessed and verbally described the patients' pain levels, but these assessments were rarely documented in the chart. Nurses were aware of the need to assess pain, but reported that they did not "have time" to chart their assessments. A medication cart was used to dispense routine medications and analgesics. The nurse signed for breakthrough analgesic medication on a "PRN and Stat Dose" medication record. The patient's chart and nursing

narrative notes were housed at the nursing station. A nurse dispensing an opioid to a patient had to return to the nursing station to document the rationale for administering breakthrough medication. This process would have to be repeated if the nurse also had to document the therapeutic effect of the pain medication.

The CNS believed that unless a more practical way was found to link nursing pain assessment and documentation, it was unlikely that nurses would find the time to chart in a timely manner. Therefore, the CNS conducted a retrospective chart audit utilizing Ferrell, Wisdom et al.'s (1991) audit tool. Approximately 50 charts of patients cared for in 1994 were audited. Following the guidelines outlined by Ferrell, Wisdom et al., one 24-hour period of documentation was chosen for review. The results of the audit confirmed that pain ratings were not consistently documented, and assessments consisted of vague descriptors such as "pain worse" or "pain does not seem to be relieved." The audit results provided the CNS with further incentive to develop a documentation tool specifically for pain assessment, and encouraged other members of the interdisciplinary team, especially the palliative care physician and pharmacist, to become involved in the development of the PATF.

The first step in developing the tool involved reviewing nursing pain assessment tools that were described in the literature and within the local community. Three tools were especially important in influencing the development of the PATF at Saint Mary's Hospital, New Westminster, British Columbia. These included the pain flowsheet by McCaffery and Beebe (1989), the nursing pain assessment flowsheet used at the BC Cancer Agency (1991), and the pain flowsheet instrument from the Vancouver General Hospital (1992).

Development of the PATF

Since so many patients were experiencing escalating and unstable pain levels, the decision was made to design a tool for a 24-hour time period. Detailed assessments were required and could not be easily portrayed on a multi-day form. The PATF (see Figure One) included four assessment and documentation sections: assessment; regular narcotics; breakthrough narcotics; and total number of milligrams in the previous 24 hours compared with total number of milligrams in the current 24 hours.

The assessment component included three possible measurements from which the nurse could choose. The first was a 5-point or 10-point visual analogue scale (VAS). The second was a verbal rating scale from "0" (no pain) to "5" (excruciating pain). The third possible rating allowed the nurse to make a behavioural observation, such as restless, agitated, or moaning, in those instances where patients could not articulate a rating. The flowsheet directed the nurse to note the location of the pain, given that patients may experience more than one site of pain. In addition, the audit had revealed that a specific description of the location of the pain was often not documented.

The nurse could also document respiratory rate, and the guidelines for use specified that this did not have to be filled in routinely, but rather on an exceptional basis for palliative care patients. Since pain is the physiological antagonist to the central depressant effects of opioids, clinically important respiratory depression is rare in cancer patients (World Health Organization, 1996). Therefore, unlike scales used to assess post-operative pain, the scales used to assess patients who are terminally ill often do not focus on respiratory rate. Respiratory rate is documented if the nurse notes the patient is sedated or shows a sudden or unexpected change in respiratory status. It is understood that any nurse assessing a patient considers the entire clinical picture and uses judgment in ascertaining changes in respiratory rate or levels of consciousness.

The next two sections of the flowsheet (regular narcotics and breakthrough narcotics) became the actual medication administration record. This allows the nurse to simultaneously document the assessment and administration of the regular narcotic dose and any breakthrough dose. A breakthrough dose is defined as a dose of medication that is essential to handle pain that "breaks through" the regular doses of pain medications, either because pain is uncontrolled or because the pain has peaked in intensity (Librach, 1991). The frequency is usually hourly and increases in amount depending on the regular opioid dose. The response to the breakthrough, in terms of the pain rating, is to be documented within one hour following its administration. A red pen is used to document breakthrough, stat, and PRN medications. The reverse side of the flowsheet is used for stat and PRN dosages of medications other than opioids. The flowsheet can also be used to document a continuous infusion of narcotics via a portable pump, thereby eliminating the need to document in multiple areas.

The bottom of the flowsheet was developed with the support and assistance of the palliative care physicians on the unit. However, patients are admitted to the unit under the care of a family physician who is generally responsible for ordering opioid medications. Comprehensive pain protocols are available which provide direction for escalating daily dosages and ordering breakthrough medications. The use of this 24-hour flowsheet presented an excellent opportunity to support decision-making by the family physician, in that it allowed the physician to compare the total milligrams (regular plus breakthrough dose) in the previous 24 hours and the total milligrams in the current 24-hour period. The number of

breakthroughs was also highlighted. Therefore, if a patient experienced numerous breakthrough doses, it was clearly documented and these doses were added to the total milligrams administered in the previous 24 hours. The new 24-hour dose was then calculated based on the objective recording of narcotic doses administered.

Objective ratings and calculations can be important educational tools in and of themselves because they highlight the need to continually assess and adjust both breakthrough and regular medication dosages. Nurses were encouraged to review the PATF with the prescribing physician, either over the phone or when the physician made a patient visit. A clear medication history provided evidence for increasing the regular or breakthrough dose. This was particularly useful for nurses who often had a dosing range from which to choose, within the context of physicians' orders.

Input was sought from all interdisciplinary team members and emphasis was placed on practicality and ease of use. Discussions took place at interdisciplinary team meetings, in meetings with nursing staff, and with family physicians involved in patients' care.

Originally, an attempt was made to also include non-opioids on the medication list since these often act as adjuncts to pain relief; e.g., amitriptyline, ibuprofen, etc. However, this became too confusing for the nursing staff because analgesics may be used for multiple reasons. For example, the same drug could be used with analgesic intent and as an anti-pyretic. Thus, it was important to review the daily medication profile along with the PATF when the overall response to pain was considered.

Figure One:

R.N. to check pain assessment tool used:

NUMERICAL	VERBAL	BEHAVIORAL OBSERVATION	ME:
0 - No pain	5 - EMUCATING	R.N. to note pain behavior:	Regular Narcotic - Black Ink
1 - Worst pain	4 - HORRIBLE	Example: restless	Breakthrough Narcotic - Red Ink
	3 - DISTRESSING	agitated	
	2 - DISCOMFORTING	crying	
	1 - MILD	moaning	
	0 - NO PAIN		

ALLERGIES: _____

DATE: from 0600 (m/y) to 0600 (m/y)

Legend:
 NN = See Narrative Notes
 BT = Breakthrough dose
 SL = Sleeping
 NR = Non Responsive

ASSESSMENT	TIME:																				
	Location																				
	Pain Assessment Rating																				
	Respiratory Rate																				
REGULAR NARCOTICS																					
BREAKTHROUGH NARCOTICS																					
	Response to B.T. - use same column as B.T. given																				
	Initials of R.N.																				
Total mg previous 24 hours (Regular & BT) _____ mg																				Total Mg current 24 hours (Regular & BT) _____ mg	
#BTs in last 24 hours _____																					
Time of last BT: _____																					

SAINT MARY'S HOSPITAL
New Westminster, B.C.
PAIN ASSESSMENT AND TREATMENT FLOWSHEET (PATF) 24 HOUR

Implementation of the PATF

The tool was presented to the hospital physician group at a meeting of the medical advisory committee. Some resistance was encountered, as the tool required physicians on the palliative care unit to review an "extra" and "different" form. Medication carts were being introduced at the hospital around the same time and physicians were concerned that medication histories would not be readily available. Access to the PATF was ensured by placing the PATF on the patient's chart by 0700 hours to support physicians in their assessment and decision-making regarding pain management.

The original PATF draft allowed the nurse or patient to choose a 0-5 or a 0-10 VAS. Feedback from nurses indicated that patients seemed to prefer a 0-5 VAS and, thus, the PATF was amended to include only the 0-5 VAS.

Nursing staff reported that the tool was easy to use. The CNS conducted additional chart audits at various times post implementation of the PATF. The audit results were favourable indicating that the PATF was being used appropriately in clinical practice. For example, most sections were completed fully and pain assessment was done at the intervals specified in the guidelines for use of the PATF. As physicians became increasingly comfortable with reviewing the tool, they would ask that nurses on other units use the tool when a patient was experiencing a complex pain problem!

Current utilization of the PATF

Informally, the palliative care nurses report that the PATF is an invaluable tool in clinical practice. It is believed to support


nursing assessment, documentation, and decision-making in clinical palliative care practice. However, a formal evaluation would be required to validate this finding. An initial pain assessment and careplan is documented in the interdisciplinary progress notes using the concept of Focus Charting® as the documentation standard (Lampe, 1997). Subsequently, the PATF is initiated and is used by the disciplines of nursing, medicine, and pharmacy to make decisions in relation to increasing and/or decreasing the regular four-hourly opioid administration, along with the one-hourly breakthrough medication administration. For a number of patients, the PATF is also used to titrate long-acting preparations.

Revisions to the PATF

The CRN surgery/medicine has recently made changes to the original PATF (see Figure One) based on a review of the literature and community standards and in collaboration with the nurses, physicians, and pharmacists using the form in palliative care. The present goal is to advance and integrate the revised PATF (see Figure Two) into palliative care and then into the general patient population. Figure Two illustrates the assessment, documentation, and decision-making of a typical patient scenario where the patient is experiencing escalating pain. The overall aim is to enhance everyday pain assessment, documentation, and decision-making in clinical practice beyond the specialty of palliative care.

Two important changes were made to the revised PATF to enhance nursing assessment and decision-making – the addition of

Figure Two:



SAINTE MARY'S HOSPITAL
New Westminster, B.C.

24 Hour Pain Assessment & Treatment Flowchart (PATF)

SEDATION SCALE:
 Sleep, easily aroused
 1 = Awake and alert
 2 = Occasionally drowsy, easy to arouse
 3 = Frequently drowsy, arousable, drifts off to sleep during conversation.
 4 = Somnolent, minimal or no response to stimuli

PAIN SCALE:
 Sleeping
 0-10 Numeric Pain Intensity Scale

0
No
Pain

5
Moderate
Pain

10
Worst
Possible
Pain

PAIN BEHAVIORS:
 Examples
 Restless
 Agitated
 Crying
 Moaning
 None

INKS:
 Regular Narcotics - Black Ink
 Breakthrough Narcotics - Red Ink

FC - Focus Charting®
 Interdisciplinary Progress Notes

DATE: from 0600 08/12/01 to 0600 09/12/01
(yy/mm/dd) (yy/mm/dd)

Patient's Consent: Graph 4 **ALLERGIES:** No known allergies

		24 HOUR											
		0600	0815	0930	1000	1600	1800	1815	2020	2200	0200	0515	
ASSESSMENT	Location	Back	Back	Ab	Ab	Ab	Ab	Ab	Ab	Ab	Ab	Ab	
	Respiratory Rate				16								
	Sedation Scale	1	1	1	1	1	1	1	1	1	2	2	
	Pain Scale/Pain Behaviors	8	6	8	10	8	10	8	8	6	6	6	
REGULAR NARCOTICS	Morphine Sulphate (MOS) 10 mg, po every 4 hrs.	10			10	10	10			10	10		
BREAKTHROUGH NARCOTICS <small>BT = Breakthrough Doses</small>	MOS 2.5 mg po every 4 hrs.		2.5	2.5				2.5	2.5			2.5	
	Response to breakthrough dose		3	4				7	4			4	
	Initials of R.N.	CT	CT	CT	CT	CT	CT	CT	BM	BM	BM	BM	
Interdisciplinary Progress Notes		✓						✓					
Total mg previous 24 hours (Regular & BT) <u>51</u> mg								Total mg current 24 hours (Regular & BT) <u>22.1</u> mg					
#BTs in last 24 hours <u>3</u>													
Time of last BT: <u>0310 hours</u>													

a patient's comfort goal and a sedation scale. The patient's comfort goal is visible on the PATF and is used to evaluate the effectiveness of the pain management plan (McCaffery & Pasero, 1999). Patients with clinically significant respiratory depression are usually also sedated because more opioid is required to produce respiratory depression than is required to produce sedation. This means that monitoring of sedation level is at least as important, if not more so, than monitoring respiratory status (Pasero & McCaffery, 1994).

Assessing and monitoring the depth and quality of respirations is a fundamental nursing assessment parameter in the general patient population. However, the meaning of a respiratory rate and its subsequent treatment may vary depending upon its clinical significance. For example, in a post-operative patient who has a respiratory rate of eight and a sedation level of "4", the antagonist Narcan® may be administered to reverse the sedative effects of the opioid and alleviate respiratory depression.

The numeric pain intensity scale was changed from 0-5, which had previously been recommended by nursing staff, to a 0-10 VAS. This change was based on the AHCPR's recommendation to use a 10-centimetre baseline if a graphic rating scale is used for a patient's self-report of pain (Acute Pain Management Guideline Panel, 1992).

The assessment category of pain behaviours remains on the PATF because we recognized that indirect methods of pain assessment, such as observation of pain behaviours or next-of-kin evaluation to estimate pain may need to be used when patients are unable or unwilling to communicate information about their pain to the caregiver (Vallerand, 1997).

Implications for nursing practice and research

As the health care system continues to evolve, nursing leadership is required to coordinate, plan, monitor, and evaluate patient care outcomes in clinical practice. By encouraging the

integration of the practice of pain assessment, documentation, and decision-making into routine practice, nursing leaders can create an environment in which nurses will be able to provide a more consistent and comprehensive approach to pain management.

Organizational programs and nursing practice need to be routinely evaluated by well-designed quantitative and qualitative research designs. These program evaluations are essential for the development and synthesis of nursing knowledge to advance the art and science of nursing practice. A comprehensive evaluation of the revised PATF is needed to demonstrate and quantify the nurses' effectiveness when using the PATF to make nursing decisions about pain management.

Conclusion

A major accomplishment of the development, implementation, and revision of the 24-hour PATF in this organization was the establishment of clinical standards of care to link the routine nursing assessment of pain, documentation, and decision-making. Integration of this standard has fostered a move toward nursing accountability for pain management in daily clinical practice.

Nursing decisions regarding pain management can be made using a combination of four assessment parameters, such as the patient's comfort goal, pain scale/pain behaviours, sedation scale, and respiratory rate. Ideally, as the PATF is integrated into the general patient population and across clinical settings, what will change is how nurses apply these assessment parameters to make decisions and, ultimately, provide appropriate pain management for all patients in all clinical settings. ♦

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President's Message

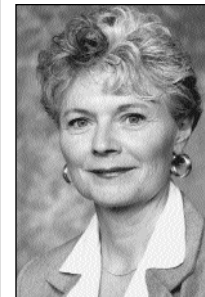
Happy new year to all CANO members! It has been a busy, productive, and exciting year for your board and executive. In addition, we are just settling in with our new management office and are beginning the work of developing an implementation plan for our strategic plan. I am happy to submit my president's speech as a guest editorial for this issue of CONJ. I gave my speech at our recent and very successful annual conference in Victoria last October. If you missed the conference, make sure you plan to attend the 2001 conference in Quebec City. Already work is well underway and this will mark the first time in our history as an organization that we have held a conference in Quebec. Expect to see more "firsts" as we burst into the new millennium! ❀

**Carolyn Tayler,
CANO President**

Message de la Présidente

Meilleurs vœux de Bonne Année à tous les membres de l'ACIO! L'année qui se termine a été, pour les membres du conseil national et du comité exécutif, une période fort occupée à la fois productive et excitante. En outre, nous nous adaptons graduellement à notre nouveau bureau administratif et nous lançons les travaux préliminaires en vue d'élaborer la mise en œuvre de notre plan stratégique. Pour ce numéro de la Revue, j'ai l'honneur de présenter le Discours de la présidente à titre d'éditorial d'invitée spéciale. Ce discours, je l'ai prononcé lors de notre conférence annuelle d'octobre qui a remporté un vif succès à Victoria. Si vous n'avez pas eu l'occasion d'y assister, projetez de participer à celle de 2001 qui, elle, se déroulera à Québec. Les travaux sont déjà bien avancés et cela sera la première fois de toute notre histoire que la conférence annuelle aura lieu au Québec. Attendez-vous à d'autres grandes premières à l'aube du nouveau millénaire! ❀

**Carolyn Tayler,
présidente de l'ACIO**



CONEP Report

By Esther Green

The Standards of Care document was shared with over 350 nurses at the CANO conference in Victoria in October 2000. All 350 members were invited to participate in an Astra Zeneca funded luncheon where the document was presented. In addition, all participants were invited to contribute to the feedback process. Questions were addressed at the presentation and during the conference. The document was accompanied by a questionnaire requesting feedback by November 15, 2000. On November 17, 18, and 19, the feedback was reviewed and used to modify the document as suggested.

Responses were received from New Brunswick, Nova Scotia, Ontario, Manitoba, Saskatchewan, Alberta, and British Columbia, along with several unidentified sources. In addition to indicating whether they agreed with the standards of care, nursing roles, role descriptions, and competencies, extensive comments were provided. The responses were tallied and comments summarized. The vast majority of responses indicated support for the document.

Supportive comments

Thank you for the opportunity to participate in this exercise. I like the layout and the way the case studies are presented. It is a wonderful document - well worth waiting for...

This is a very thoughtful and comprehensive document. I hope it will be a useful document for the practising oncology nurse...

May I first say what a pleasure it was to read this document and to feel the essence of what we do within the words. It is an amazing piece of work...

Excellent job - well done. This is an exciting advance for oncology nursing in Canada...

This document, if used as intended, could be a very useful tool to the overall oncology nursing practice within my facility...

This is a wonderful document. It captures the full potential of oncology nursing in a clean, concise way. I dream of the day when employers will state that their employee expectations are based on the CANO standards...

Expressed concerns

While there was overwhelming support for the document, concerns expressed by individuals included:

It is also very academic and a tough document to get through...

Grammatical errors and sentence structure issues are present...

The absence of the "novice to expert" progression in the description of nursing roles...

The "measurability and objectivity" of the standards, and the absence of terminology congruent with Bloom's taxonomy

Clarity of terminology

Recommendations

- present the information in a way that the reader could see the progression between nursing roles, and the link of these roles with the standards of care
- add scenarios that focus on screening, and on palliative care
- use the CNA framework for describing the advanced oncology nurse role
- include intradisciplinary roles and valuing within the descriptions and rationale

Resulting modifications to the document

- addition of a figure to elaborate the relationship between roles and standards of care
- alterations in and development of the scenarios to capture screening and palliative care and to make the fit between scenario and standard clearer
- updating of the terminology and definitions
- clarification of the CNA framework in relation to describing the advanced oncology nurse role
- correction of grammatical and spelling errors
- inclusion of the concept of "novice to expert" in the description of roles
- clarification of the competencies

Rapport du CONEP

Rapport du Projet canadien de formation infirmière en oncologie (CONEP)

Par Esther Green

Le document Normes de soins a été distribué à plus de 350 infirmières au cours de la conférence de l'ACIO qui s'est déroulée à Victoria en octobre 2000. Les 350 membres étaient tous invités à assister à un dîner subventionné par Astra Zeneca pour marquer la présentation du document. On encourageait toutes les participantes à fournir commentaires et suggestions. On a abordé les questions émanant de l'auditoire durant la présentation elle-même et dans le cadre de la conférence. Le document s'accompagnait d'un questionnaire qui devait être renvoyé le 15 novembre au plus tard. Et les 17, 18 et 19 novembre, on a passé en revue les suggestions et commentaires reçus et on a modifié le document en conséquence.

Des commentaires et suggestions nous sont parvenus du Nouveau-Brunswick, de la Nouvelle-Écosse, de l'Ontario, du Manitoba, de la Saskatchewan, de l'Alberta et de la Colombie-Britannique ainsi que de quelques endroits non identifiés. Leurs auteurs, en plus d'indiquer s'ils étaient d'accord avec les normes de soins, les rôles infirmiers, les descriptions de rôles et de compétences, fournissaient des commentaires détaillés. On a dressé le bilan de la rétroaction et fait le résumé des commentaires. Dans leur vaste majorité, les répondants indiquaient qu'ils appuyaient le document.

Commentaires positifs

Merci de me donner l'opportunité de participer à cet exercice. J'aime la mise en page et la présentation des études de cas. C'est un merveilleux document et l'attente en valait la peine...

Voilà un document complet bien pensé. J'espère qu'il deviendra un outil utile pour

l'infirmière en oncologie dans le cadre de sa pratique...

J'aimerais d'abord vous parler du plaisir que j'ai éprouvé à la lecture de ce document et vous dire que je juge que les mots utilisés reflètent l'essence de notre profession. Une œuvre étonnante!...

Bravo, c'est une réussite! Il s'agit là d'un grand pas pour les soins infirmiers en oncologie du Canada...

Ce document, s'il est utilisé tel que prévu, pourrait devenir un outil très utile à la promotion de la pratique infirmière en oncologie dans mon établissement...

Ce document est tout simplement merveilleux. Il traduit le potentiel global des soins infirmiers en oncologie d'une manière nette et concise. J'attends avec impatience le jour où les employeurs annonceront que leurs attentes en matière de rendement des employés sont basées sur les normes de l'ACIO...

Rapport du CONEP

Préoccupations exprimées

Quoique dans l'ensemble, le document jouisse d'un appui incontesté, certaines personnes ont émis des inquiétudes à son sujet, dont:

Ce document ne se lit pas facilement à cause de sa nature théorique...

Il comporte des erreurs grammaticales et la structure des phrases laisse à désirer...

On note l'absence d'une progression «de novice à expert» dans la description des rôles infirmiers...

Le caractère mesurable et objectif des normes et l'absence d'une terminologie congruente à la taxonomie de Bloom...

Clarté de la terminologie...

Recommandations

- présenter l'information de manière à ce que les lecteurs voient la progression d'un rôle infirmier à un autre ainsi que le lien entre les rôles et les normes de soins
- ajouter des scénarios axés sur le dépistage et sur les soins palliatifs
- reprendre le cadre de l'AIC pour décrire le rôle de l'infirmière en oncologie en pratique avancée
- incorporer, dans les descriptions et le fondement, des rôles intradisciplinaires et valoriser ces derniers

Modifications apportées au document

- ajout d'une figure visant à expliquer le rapport entre les rôles et les normes de soins

- développement et modification des scénarios afin d'aborder le dépistage et les soins palliatifs et de clarifier la correspondance scénario-norme
- actualisation de la terminologie et des définitions
- clarification du cadre inspiré de celui de l'AIC en ce qui concerne la description du rôle de l'infirmière en oncologie en pratique avancée
- correction des fautes d'orthographe et des problèmes grammaticaux
- incorporation du concept de gradation «de novice à experte» dans la description des rôles
- clarification des compétences

Strategic Planning

Strategic planning – An update

By Linda Masko

This summer, all CANO members received by mail a copy of our strategic plan, "Leadership through partnership and action." It provided the reader with a summary of the process and the activities that have taken place since April 1998. Included in the document were the six new strategic directions and corresponding goals of the

organization which will provide a roadmap for CANO's future and the continued development of oncology nursing as a specialty.

At the board of directors' meeting and the annual general meeting held during the fall conference in Victoria, the strategic planning process was discussed with the following outcomes:

- All strategic directions will be addressed simultaneously
- The work will be done with an approach that is fiscally feasible yet comprehensive

- Broad input from membership is required
- Working groups would be struck based on geographic location (see Table One)

A provincial director will take responsibility for ensuring that the work gets done. This person could actually be involved in the work or act as liaison. The working groups will develop recommendations with a national focus and set a framework for discussion. This document will be submitted to the board for approval at the 2001 spring board meeting.

One of the six strategic directions is standards and it is spearheaded by the Canadian Oncology Nursing Education Project (CONEP). CONEP will remain a special initiative. Any member is invited to submit comments regarding this strategic direction to CONEP's co-chairs Esther Green or Barb Love.

How can you be part of this exciting process? Have a say! Access CANO's website (www.cos.ca) under strategic planning and submit your ideas, comments, or suggestions; become part of a work group by contacting your provincial director; or discuss the strategic plan in your local chapter and give us your feedback. Please feel free to contact me at any time if you have any comments or questions.

On CANO's behalf, I would like to thank and recognize the British Columbia Oncology Nursing Group (BCONG) and the Oncology Nurses Interest Group of Alberta (ONIGA) for their generous financial donations which will help support the implementation of the strategic plan.

Linda Masko, is CANO vice-president and project leader for strategic planning.

Table One: Working groups

Geographic area	Strategic direction	Provincial director
British Columbia	Membership recruitment	Chris Emery
Ontario	Fiscal stability	Donalda MacDonald
Alberta Saskatchewan Manitoba	Leadership/Profile (two-year time frame)	Sylvia Huber Denise Budz Donna Romaniuk
Quebec	Patient advocacy (two-year time frame)	Linda Hershon
Nova Scotia New Brunswick Newfoundland Prince Edward Island	Organizational infrastructure	Cathy Walls Jean Manship Kathy Fitzgerald Mary Pagé
CONEP	Standards	Esther Green/Barb Love

Planification stratégique

Planification stratégique – Dernières nouvelles

Par Linda Masko

L'été dernier, tous les membres de l'ACIO ont reçu par la poste un exemplaire du Plan stratégique: «Un leadership caractérisé par le partenariat et l'action». Il proposait aux lectrices un résumé du processus et des activités réalisées depuis avril 1998. Le document présentait également les six nouvelles orientations stratégiques de notre organisme et les objectifs correspondants, qui guideront l'avenir de l'ACIO et le développement continu des soins infirmiers en oncologie en tant que spécialité.

Lors des réunions du Conseil national et de l'Assemblée générale annuelle tenues dans le cadre de la conférence de Victoria, les discussions portant sur le processus de planification stratégique se sont soldées par les résultats suivants:

- Toutes les orientations stratégiques seront traitées simultanément
- Les travaux adopteront une approche globale tout en tenant compte des limites financières d'un tel exercice
- On attend des membres de l'organisme qu'ils participent activement au processus
- Des groupes de travail seront établis sur une base géographique (voir le tableau 1)

Une des représentantes provinciales sera responsable de la bonne conduite des travaux. Cette personne pourrait y participer directement ou bien y jouer un rôle de liaison. Les groupes de travail élaboreront des recommandations d'envergure nationale et établiront un cadre pour la discussion. Ce document sera présenté au Conseil national à des fins d'approbation à l'occasion de la réunion du printemps 2001 de ce dernier.

Les Normes constituent l'une de nos six orientations stratégiques, et ce projet

particulier est animé par le CONEP (Projet canadien de formation infirmière en oncologie). Le CONEP gardera son statut d'initiative spéciale. Tous les membres de l'ACIO sont invités à faire parvenir leurs commentaires sur cette orientation stratégique à l'une ou à l'autre des coprésidentes du CONEP, Esther Green et Barb Love.

Aimeriez-vous participer à ce processus des plus excitants? Exprimez donc votre point de vue. Rendez-vous au site Web de l'ACIO (www.cos.ca) et allez à l'item *Strategic Planning* et soumettez vos idées, commentaires et suggestions; vous pouvez siéger à un groupe de travail en communiquant avec votre représentante

provinciale; ou bien abordez le plan stratégique dans votre section locale et faites nous part de vos conclusions. N'hésitez pas à me contacter en tout temps si vous avez des commentaires ou des questions.

Au nom de l'ACIO, j'aimerais remercier le BCONG (Groupe des infirmières en oncologie de la C.-B.) et l'ONIGA (Groupe d'intérêt des infirmières en oncologie de l'Alberta) pour leurs dons généreux qui serviront à appuyer la mise en œuvre du plan stratégique. ✿

Linda Masko est vice-présidente de l'ACIO / responsable de projet, Planification stratégique.

Tableau 1 : Groupes de travail

Zone géographique	Orientation stratégique	Représentante provinciale
Colombie-Britannique	Recrutement des membres	Chris Emery
Ontario	Stabilité financière	Donalda MacDonald
Alberta Saskatchewan Manitoba	Leadership / Visibilité (sur une période de 2 ans)	Sylvia Huber Denise Budz Donna Romaniuk
Québec	Défense des intérêts des patients (sur une période de 2 ans)	Linda Hershon
Nouvelle-Écosse Nouveau-Brunswick Terre-Neuve Île-du-Prince-Édouard	Infrastructure organisationnelle	Cathy Walls Jean Manship Kathy Fitzgerald Mary Pagé
CONEP	Normes	Esther Green / Barb Love

CANO Awards

2000 CANO Awards Report

By Janet Templeton

CANO/Amgen Award for Innovation in Oncology Patient and Family Education

The Award for Innovation in Oncology Patient and Family Education is the result of a partnership between CANO and AMGEN Canada and was presented for the third time at the Victoria conference.

Nurses whose primary function is the provision of direct patient and family care often face significant challenges in providing information that cancer patients require to cope effectively with their condition. This award recognizes the achievements of nurses who have met the challenges and who have exhibited creativity in the development of patient education materials or programs, or in the delivery of patient education.

The recipients of the award for 2000 were three nurses who developed an educational tool for patients receiving bisphosphonate infusions. Margie Macgregor, Dianne Taylor, and Wendy Birch all work in the oncology

clinic at Lakeridge Health Care Corporation in Oshawa, Ontario.

These oncology nurses have developed an educational tool which is used in their clinic for patients receiving bisphosphonate infusions. Patients were coming as outpatients to the oncology clinic to receive their infusions via the traditional intravenous route. Seeing the need to improve their patients' quality of life, these nurses developed a program for the patient and caregiver to educate them on how to self-administer this infusion in the comfort of their own home using an elastomeric infusion device. This has greatly improved the quality

CANO Awards

of life of their patients by allowing them to regain their independence.

On behalf of the CANO Recognition of Excellence Committee, I wish to extend congratulations to Margie Macgregor, Dianne Taylor, and Wendy Birch.

Pharmacia and CANO Awards of Excellence Program

This Pharmacia and CANO Awards Program is designed to recognize individuals who have exhibited leadership and excellence in cancer nursing. Four awards of excellence are available for Canadian oncology nurses recognizing excellence in the areas of practice, education, research, and administration.

The recipient of the **Practice Award of Excellence** for 2000 is Jean Manship. Jean is the clinical resource nurse for oncology and medicine at the South East Health Care Corporation in Moncton, New Brunswick. For the past 18 years, Jean has worked in oncology and is said by her colleagues to exemplify the qualities of leadership, professionalism, and excellence in oncology nursing. Her vision of oncology nursing has been instrumental in developing the oncology program at her hospital. Jean strongly believes in a holistic approach to patient care and promotes early intervention from nursing as soon as the diagnosis of cancer is made.

As the resource nurse for oncology, Jean has assisted staff nurses in their educational preparation for the certification exam in oncology nursing and she promotes the expertise of these nurses throughout the hospital.

She lives her professionalism in her daily life and reflects her joy of nursing to her peers. Jean is known to have a positive influence on her peers as she demonstrates her dedication and commitment to improving the quality of health care for patients with cancer. She has endeavoured to educate herself, staff, patients, and families in new and innovative approaches to cancer care delivery. She has presented at many conferences and has developed many educational tools for patients in her hospital.

In 1999, Jean was recognized by her peers in her home province as the recipient of the Nurses Association of New Brunswick Award for Excellence in Clinical Practice. On behalf of the CANO Recognition of Excellence Committee, I want to congratulate Jean Manship for demonstrating excellence in oncology nursing practice.

The recipient of the **Education Award of Excellence** for 2000 is Barbara Wilson.

Barbara is the nurse educator at the Princess Margaret Hospital in Toronto, Ontario as well as an educator with the post-RN oncology certification program at Centennial College. Barbara is described by her peers as an innovative, dynamic, and brilliant educator. Her attention to the principles of adult learning has gained her a reputation as an excellent facilitator of learning at her centres.

Barbara has excellent interpersonal skills and has a friendly and caring approach which has fostered the sharing of knowledge and ideas among nurses across the country. She always finds time in her busy schedule to support and educate any nurse who seeks her assistance. She gives encouragement and credit to other nurses through guidance in the development of patient education materials, rather than taking over the project herself.

Staff at her centre feel very fortunate to have Barbara's support and guidance, and they apply to take any course she is listed as teaching as she offers both informative and fun sessions. She is said to leave you with a wealth of knowledge which you are ready to use.

Most recently, Barbara has been asked to implement the testing of one of her province's nursing association's best practice standards. This demonstrates the respect for her expertise and reflects the value placed on her leadership.

On behalf of the CANO Recognition of Excellence Committee, I wish to congratulate Barbara Wilson for demonstrating excellence in oncology nursing education.

The 2000 recipient of the **Research Award Of Excellence** is Linda Hershon. Linda is the clinical research nurse at the St. Justine Hospital in Montreal. Linda has worked in oncology nursing for 21 years. She is actively involved in research within her profession and she assists her colleagues in implementing research findings into practice.

Linda ensures the staff nurses are educated in the clinical trials with which she is involved. Her patients and families truly appreciate the time she takes to explain the protocols to them. She ensures that her patients fully understand the treatment they will receive.

Linda is responsible for orientating new nurses and acts as a preceptor for oncology nurses in clinical trials. She is also responsible for creating all phase I program trials at her hospital.

She is a member of the Clinical Trials Nurse Special Interest Group with the NCIC. She has published and presented nursing research at conferences. She is an active CANO member locally and represents her province on the national board of CANO. She is a member of the CANO Research

Committee and is on the National Pain Initiative.

On behalf of the CANO Recognition of Excellence Committee, I want to congratulate Linda Hershon for demonstrating excellence in oncology nursing research.

The recipient of the 2000 **Administration Award of Excellence** is Sue Ness. Sue is the program administrative director with the Extra Mural Program, Atlantic Health Sciences Corporation in New Brunswick. Sue is described as a responsible and accountable person who is respected for her experience in and contributions to oncology nursing. She demonstrates excellent "people skills", and with her easy style of management, leaves her co-workers singing her praises. She gives 100% of herself to her work and to the people she works with.


Sue's commitment to her work and her ability to maintain a balance between work and her family and friends is truly amazing. She has a caring attitude which is always patient-focused. She demonstrates a positive attitude in her administrative role. Her warm smile has touched the lives of many people and her love of life is contagious. She is a strong believer in team work and collaboration, and believes in discovering and recognizing the gifts others have to offer.

Sue has been a member of many provincial and national committees representing oncology nursing in her role as administrator and leader within the oncology nursing community. She has been a leader in CANO for many years, and co-chaired the national CANO conference when it was held in her province. She is committed to promoting the mission and vision of CANO locally, provincially, and nationally.

On behalf of the CANO Recognition of Excellence Committee, I want to congratulate Sue Ness in demonstrating excellence in oncology nursing administration.

Additional awards

The **Ross First Time Presenter Award** was presented to Rosemary Horlin and Pam Potter. The title of their presentation was *The role of spirituality in the care of pediatric oncology patients, families, and staff*.

Finally, the recipient of the **Bard Best Poster Award** was Marni Besser from the BC Cancer Agency for her poster entitled *Symptom management of patients receiving stereotactic radiosurgery*. 

Submitted by Janet Templeton, Chairperson, Recognition of Excellence Committee.

Prix décernés

Conférence 2000 – Rapport sur les prix décernés

Par Janet Templeton

Prix d'innovation dans l'enseignement aux patients en oncologie et à la famille ACIO/Amgen

Le **Prix d'innovation dans l'enseignement aux patients en oncologie et à la famille** est le résultat d'un partenariat entre l'ACIO et Amgen Canada; il a été décerné, pour la troisième fois, dans le cadre de la conférence de Victoria.

Les infirmières chargées principalement de la dispensation de soins directs aux patients et à leur famille doivent souvent relever des défis importants lorsqu'il leur faut fournir aux patients atteints de cancer l'information nécessaire à une adaptation efficace à la maladie. Ce prix reconnaît les réalisations d'infirmières qui ont franchi les obstacles et ont fait preuve de créativité relativement à l'élaboration de matériel ou de programmes éducatifs à l'intention des patients ou à la prestation de l'enseignement aux patients.

Les récipiendaires du prix de l'an 2000 sont trois infirmières qui ont mis au point un outil pédagogique à l'intention des patients suivant des cures de bisphosphonates. Margie Macgregor, Dianne Taylor et Wendy Birch travaillent toutes trois à la clinique d'oncologie de la Lakeridge Health Care Corporation d'Oshawa, Ontario.

Ces infirmières en oncologie ont élaboré un outil éducatif au profit des patients de leur clinique suivant des cures de bisphosphonates. Les patients s'y rendaient pour recevoir, en clinique externe, leurs perfusions par la voie intraveineuse conventionnelle. Réalisant qu'elles se devaient d'améliorer la qualité de vie de ces patients, nos trois infirmières ont mis au point un programme destiné aux patients et aux soignants visant à leur enseigner comment assurer eux-mêmes l'administration de la perfusion dans le confort de leur propre demeure à l'aide d'un système de perfusion en élastomère. Elles ont ainsi grandement amélioré la qualité de vie de ces patients en leur permettant de retrouver leur autonomie.

Au nom du Comité de reconnaissance de l'excellence de l'ACIO, j'adresse toutes mes félicitations à Margie Macgregor, Dianne Taylor et Wendy Birch.

Programme de prix d'excellence Pharmacia - ACIO

Ce programme de prix d'excellence offert conjointement par la compagnie Pharmacia et l'ACIO a pour but de reconnaître le leadership et l'excellence dans les soins infirmiers en oncologie. Quatre prix viennent récompenser l'excellence dans les domaines de la pratique, de l'éducation, de la recherche et de l'administration.

Pour l'année 2000, la lauréate du **Prix d'excellence pour la pratique** est Jean Manship. Mme Manship est infirmière clinicienne-ressource pour l'oncologie et la médecine à la South East Health Care Corporation de Moncton, Nouveau-Brunswick. Voilà 18 ans que Mme Manship œuvre dans notre spécialité et ses collègues affirment qu'elle fait preuve de leadership, de professionnalisme et d'excellence dans les soins infirmiers en oncologie. Sa vision des soins infirmiers en oncologie a joué un rôle vital dans l'établissement du programme d'oncologie de son hôpital. Mme Manship soutient ardemment une approche holistique des soins aux patients et favorise, pour les soins infirmiers, une intervention précoce dès l'annonce du diagnostic de cancer.

En tant qu'infirmière-ressource en oncologie, Mme Manship a prêté main-forte aux infirmières de chevet qui se préparent en vue de l'examen de certification en soins infirmiers en oncologie et fait la promotion de l'expertise de ces infirmières à l'échelle de son établissement.

Son professionnalisme caractérise sa vie quotidienne et reflète, pour ses collègues, son bonheur d'œuvrer en soins infirmiers. Mme Manship exerce une influence positive sur ses pairs en faisant preuve d'engagement et de dévouement dans ses efforts d'amélioration de la qualité des soins de santé prodigués aux patients vivant avec le cancer. Elle s'est efforcée d'assurer son propre perfectionnement professionnel ainsi que la formation du personnel, des patients et des proches en faisant appel à des approches nouvelles et innovatrices en matière de prestation des soins aux personnes atteintes de cancer. Elle a fait des présentations dans le cadre de diverses conférences et a élaboré de nombreux outils pédagogiques à l'intention des patients de son établissement.

En 1999, Mme Manship avait déjà été reconnue par les pairs de sa province natale où l'Association des infirmières et infirmiers du Nouveau-Brunswick lui avait décerné son prix d'Excellence en pratique clinique. Au nom du Comité de reconnaissance de l'excellence de l'ACIO, je tiens à féliciter

Jean Manship d'avoir fait preuve d'excellence dans la pratique des soins infirmiers en oncologie.

En 2000, le **Prix d'excellence pour l'enseignement** a été remis à Barbara Wilson. Mme Wilson est infirmière enseignante au Princess Margaret Hospital de Toronto, Ontario, et elle enseigne également le Programme de certification en oncologie post-diplôme du Centennial College. Selon ses pairs, Mme Wilson est une éducatrice qui brille par ses innovations et son dynamisme. L'attention qu'elle porte aux principes de l'apprentissage des adultes lui a valu une réputation d'animatrice d'apprentissage hors pair dans tous les centres où elle a travaillé.

Mme Wilson possède d'excellentes habiletés interpersonnelles, et son approche cordiale et bienveillante a favorisé l'échange d'idées et de connaissances chez des infirmières d'un peu partout au Canada. En dépit de son horaire chargé, elle trouve toujours le temps d'appuyer les efforts et l'apprentissage des infirmières qui recherchent son aide. Plutôt que de prendre la direction des projets, elle préfère encourager les infirmières en les guidant lors de l'élaboration de matériel d'enseignement aux patients et leur attribuer tout le mérite du travail.

Ses collègues s'estiment heureuses de pouvoir disposer de l'appui et des conseils de Mme Wilson et elles s'inscrivent à tous les cours qu'elle offre puisque ceux-ci sont invariablement informatifs et amusants. On dit d'elle qu'elle transmet une mine de connaissances prêtes à l'emploi.

Plus récemment, l'une des associations infirmières provinciales auxquelles Mme Wilson adhère lui a demandé de mettre en œuvre la mise à l'essai de ses normes en matière de pratiques exemplaires. Ceci dénote le respect dont elle jouit pour son leadership, et la valeur de son expertise.

Au nom du Comité de reconnaissance de l'excellence de l'ACIO, je tiens à féliciter Barbara Wilson d'avoir fait preuve d'excellence dans l'enseignement des soins infirmiers en oncologie.

Le **prix d'excellence pour la recherche** est allé à Linda Hershon. Mme Hershon est infirmière en recherche clinique à l'hôpital Sainte-Justine de Montréal. Infirmière en soins infirmiers en oncologie depuis 21 ans, elle participe activement à des projets de recherche au sein de sa spécialité et aide ses collègues à mettre en œuvre les résultats de recherche dans leur pratique.

Mme Hershon veille à ce que les infirmières de chevet se familiarisent avec les essais cliniques auxquels elle participe. Ses patients et leurs proches apprécient vraiment le temps qu'elle passe à leur expliquer les

Les prix décernés

détails des protocoles. Elle tient à ce que ses patients comprennent pleinement le traitement qu'ils sont sur le point de recevoir.

Mme Hershon est chargée de l'orientation des nouvelles infirmières et joue le rôle de préceptrice auprès des infirmières en oncologie en essais cliniques. Elle a également la responsabilité de l'élaboration de tous les essais de phase I dans son établissement.

Elle est membre du Groupe d'intérêts spéciaux des infirmières en essais cliniques de l'INCC. Elle a publié des articles sur ses recherches en soins infirmiers et a donné diverses présentations dans le cadre de conférences. Elle s'implique activement dans les affaires locales de l'ACIO et représente sa province au conseil national de notre association. Elle est également membre du Comité de la recherche de l'ACIO et de l'Initiative nationale sur la douleur.

Au nom du Comité de reconnaissance de l'excellence de l'ACIO, je tiens à féliciter Linda Hershon d'avoir fait preuve d'excellence dans la recherche sur les soins infirmiers en oncologie.

Quant au **Prix d'excellence pour l'administration**, il a été décerné, en 2000, à Sue Ness. Mme Ness est directrice administrative de programme, Programme extra-mural, Corporation des sciences de la

santé de l'Atlantique au Nouveau-Brunswick. On voit en elle une personne responsable dont l'expérience en soins infirmiers et les contributions lui ont mérité le respect de tous. Ses remarquables compétences interpersonnelles et la souplesse qui caractérise son style de gestion lui méritent les louanges de ses collègues. Elle donne 100 % de son énergie à son travail et aux personnes qui l'entourent.

On ne peut qu'admirer l'engagement de Mme Ness envers son travail et sa capacité à maintenir un équilibre entre ce dernier et sa famille et ses amis. Sa bienveillance reste continuellement axée sur les patients. Elle fait montre d'une attitude positive dans son rôle d'administratrice. Elle a touché la vie de bien des gens par son sourire chaleureux, et sa joie de vivre est contagieuse. Elle croit ardemment dans le travail d'équipe et la coopération et s'efforce de découvrir et de valoriser les dons d'autrui.

Son rôle d'administratrice et de chef de file des soins infirmiers en oncologie a naturellement amené Mme Ness à siéger dans de nombreux comités provinciaux et nationaux associés à notre spécialité. Voilà déjà plusieurs années qu'elle fait partie des chefs de file de l'ACIO, et elle a coprésidé la conférence nationale de l'ACIO lorsqu'elle s'est déroulée dans sa province. Elle se

dévoue à la promotion de la mission et de la vision de l'ACIO à l'échelle locale, provinciale et nationale.

Au nom du Comité de reconnaissance de l'excellence de l'ACIO, je tiens à féliciter Sue Ness d'avoir fait preuve d'excellence dans l'administration en soins infirmiers en oncologie.

Autres prix

Le Prix des Laboratoires Ross pour la première présentation orale a été décerné à Rosemary Horlin et à Pam Potter. Leur présentation s'intitulait *The role of spirituality in the care of pediatric oncology patients, families, and staff* [Rôle de la spiritualité dans les soins prodigués aux patients en oncologie pédiatrique, aux proches et au personnel].

Enfin, le **Prix Bard pour la meilleure affiche** a été remis à Marni Besser de la BC Cancer Agency pour son affiche intitulée *Symptom management of patients receiving stereotactic radiosurgery* [Gestion des symptômes des patients recevant une radiochirurgie stéréotaxique].

Janet Templeton est présidente du Comité de reconnaissance de l'excellence.

CANO/ACIO participates in the Canadian Strategy for Cancer Control stakeholder meeting

By Kim Chapman

The Canadian Strategy for Cancer Control is hosting a stakeholder meeting in February 2001. CANO/ACIO will be one of approximately 250 individuals/organizations participating. Participants are able to review the varied reports produced by the working groups over the past two years. Reports focus on a range of topics and cross-cutting themes including prevention, screening, diagnosis, treatment, supportive care/rehabilitation, palliative care, pediatric cancer, genetics, human resources planning, informatics and technology, research, and surveillance. A synthesis document has also been produced. The synthesis document highlights recommendations for cancer care in Canada at present and in the future. For more information on the Canadian Strategy for Cancer Control or to view the reports and synthesis document go to <http://www.hc-sc.gc.ca/hppb/csc/csc.html>.

Kim Chapman is CANO representative for the Canadian Strategy for Cancer Control.

The Palliative Special Interest Group

By Janice Chobanuk

The Palliative Special Interest Group met on October 17, 2000, at the CANO conference in Victoria, B.C., to discuss the preliminary terms of reference of this special interest group and to identify objectives for the upcoming year. A few of the exciting topics discussed included the encouragement of SIG members to submit abstracts for future CANO conferences, practice tips in the area of supportive care, participation in book reviews for the **Canadian Oncology Nursing Journal**, and passing on ideas for new topics and excellent speakers for upcoming conferences.

The members indicated their commitment to this special interest group and the importance of keeping a strong palliative care profile in CANO. We agreed to meet annually at CANO conferences to share ideas, research, and to develop stronger linkages to the Canadian Palliative Care Association. A suggestion was made to change the name, "Palliative Special Interest Group", to "Supportive Care and Palliative Special Interest Group" to better reflect our interests and attract more members. We would be interested in receiving feedback from the membership on this title change. Contact Janice Chobanuk at janicech@cancerboard.ab.ca or (780) 432-8223 if you are interested in getting involved in this small but dynamic group. Please let us know who you are, as well as your address (including e-mail addresses).

CANO Conference 2000

2000 CANO conference highlights

The twelfth annual CANO conference in Victoria was well-attended by over 370 oncology nurses from across the country who enjoyed a wonderful conference in the B.C. fall sunshine (interspersed with a little rain). Delegates were offered plenty of choice with 79 concurrent papers and 22 poster presentations. Between the plenaries, concurrent sessions, posters, exhibits,

educational sessions, and social activities, it was difficult to fit in the many interesting opportunities.

The Sunday evening opening set the tone for the conference when the "Queen" attended and conferred honorary titles on Carolyn Tayler and Serge Micheli. There was much laughter as she pulled a large sword from her dress and prepared to perform the ceremony.

The keynote speakers were excellent and the lectureships were well-received, each adding a different dimension to the

conference. You will have the opportunity to read many of these presentations in upcoming issues of the journal.

Finally, the evening at Sooke was an experience for participants who had not travelled on school buses for many years! An enjoyable time was had by all and never before had the woodcarving organizers seen such a rush of people when they called for volunteers! Thank you to all who made this event and the entire conference such a success. 🌟



Photos - clockwise from upper left: Enjoying the ambience at the BC Museum; the beautiful quilt made by Jan Hill (left); Ken Stratford being presented with a gift by Heather Watson; and carved stools at Sooke.



Une bonne ambiance régnait au Musée royal de la C.-B.; la ravissante courtepointe créée par Jan Hill (à gauche); Ken Stratford reçoit un cadeau des mains de Heather Watson; et tabourets sculptés à Sooke.

Conférence de l'ACIO de 2000

Points saillants de la conférence de l'ACIO de 2000

La 12^e conférence annuelle de l'ACIO tenue à Victoria a attiré plus de 370 infirmières en oncologie de l'ensemble du Canada qui ont assisté à une merveilleuse conférence et ont profité du soleil automnal de la Colombie-Britannique (bien que la pluie soit aussi au rendez-vous). Les congressistes avaient l'embarras du choix avec 79 présentations d'articles et 22 présentations par affiches. Il y avait tant de séances plénières et concomitantes, de présentations par affiches,

d'expositions, de séances de formation et d'activités sociales qu'il était difficile d'établir son propre programme et impossible de profiter de toutes les occasions offertes.

La cérémonie d'ouverture du dimanche soir a inauguré la conférence sur une note humoristique. C'est ainsi que la «Reine d'Angleterre» a conféré des titres honorifiques à Carolyn Tayler et à Serge Micheli. Tout le monde a bien ri quand elle a sorti une longue épée de son décolleté et s'est préparée à accomplir le rituel.

Les conférencières et le conférencier étaient excellents et les articles présentés dans le cadre des prix de conférence de

l'ACIO captivaient l'auditoire et abordaient chacun une facette différente de la conférence. Vous aurez d'ailleurs l'occasion de lire une grande partie de ces présentations dans les prochains numéros de la Revue.

Enfin, la soirée passée à Sooke fut toute une expérience pour les participantes qui n'étaient pas montées à bord d'un autobus scolaire depuis fort longtemps! Tout le monde s'est bien amusé et les organisateurs de l'activité de sculpture sur bois n'avaient jamais vu un tel raz-de-marée enthousiaste quand ils ont demandé des bénévoles! Merci à toutes celles et à tous ceux qui ont assuré le succès de cette activité et de la conférence toute entière. 🌟

CANO Conference 2000 - presenters

CANO 2000 paper, poster, and workshop presenters

HELENE HUDSON

MEMORIAL LECTURESHIP

Tranmer, Joan, RN, PhD: Decisional role in seriously ill hospitalized cancer patients near the end of life: The patient's and nurse's perspective.

SCHERING LECTURESHIP

Janes, Karen, RN, MSN and Robinson, Carole RN, PhD: "Is my mom going to die?" Answering children's questions when a family member has cancer.

PAPERS

Ali, Val, RN, BA, OCN; Falconer, Marg, RN, CON(C): Patient satisfaction: Has a post-autologous stem cell transplant long-term follow-up clinic met the grade?

Anderson, Fern, RN, BSN; Hill, Jan, RN, BSN, CON(C): A model for continuing professional development: Weaving nursing education and clinical practice.

Benjaminson, Patricia, RN; Boitson, Shauna, RN; Howell, Karen, Quality Systems Associate; Loughery, Joanne, RN; Ramesar, Kathy, RN: Pre-BMT patient and family education sessions about blood and marrow transplants.

Bennett, Jocelyn P., RN, MScN, CON(C): Evidence based - ethically based: Resource allocation by any other name?

Blakeley, Judith A., RN, BScN, MBA; Ribeiro, Violeta, RN, DNSc; Crocker, Jan, RN, BN: Parent satisfaction with education, support, and decision-making regarding their children's central venous access devices.

Bodell, Kathy, RN, MSN: Surviving within the perimeter: How palliative care patients make meaning of living while dying of terminal cancer.

Boyd, M. Denise, RN: A clinical nurse perspective on GOCISTTM (Gynecological Oncology Clinical Information System).

Brooks, Laura, RN, MScN, ACNP; Williams, Diane, RN, MN; Huggins, Mary Anne, MDCM, CCFP: Advanced practice nurses and the issue of teamwork: A collaborative practice model for patient care at Princess Margaret Hospital.

Cooper, Elizabeth, RN; Palmer, Allison, RN: A new frontier: Palliative care in an ambulatory care centre.

Cordi, Carolyn, RN; Kiteley, Cathy, RN, MSc, CON(C); Bovaird, Rev. Mary Dodge, MDiv: Threading the loom.

Coulter, Lynn, RN, MN; Downe-Womboldt, Barbara, RN, PhD; Butler, Lorna, RN, PhD; Bowen, Katherine, PhD: Optimism, coping, and psychological well-being among people with advanced lung cancer.

Deane, Karen, RN, MN; Fitch, Margaret, RN, PhD; Gray, R., PhD; Howell, Doris, RN, MScN: Patient perceptions of ovarian cancer.

Deane, Karen, RN, MN; Fitch, Margaret, RN, PhD; Alex Murray, J., PhD; McKillop, Ian, PhD; Gowing, Jim, MD; Best, Dawn, RN, MSc; Ritchie, Pat, RN: Supportive care needs for cancer patients receiving ambulatory care treatment: A pilot study.

Des Rochers, C., RN, CON(C); Bakker, D., RN, PhD; McChesney, C., RN, BScN; Fitch, M., RN, PhD: Community chemotherapy clinics: Patients' perspectives.

Emery, Chris, RN, BSN, CON(C): "Thinking family" in the assessment of cancer patients.

Ennis, Helen, RN: Developing a community based palliative care program with training for volunteers.

Fitch, Margaret, RN, PhD; Gray, Ross, PhD; Franssen, Edmee, MSc; Howell, Doris, RN, MScN: Living with ovarian cancer: Perspectives of older women.

Fitch, Margaret, RN, PhD; Gray, Ross, PhD; McGowan, Tom, MD; Brunskill, Ian, MBA, CHE; Bezjak, Andrea, MD; Sellick, Scott, PhD; Steggle, Shawn, PhD; Deane, Karen, RN, MN; McLeese, Donna, RT(T): The experience of Ontario cancer patients receiving radiation treatment.

Fitzsimmons, Barb, RN, BSN: Leadership in oncology nursing - The courage to care.

Gabel, Nancy, RN, OCN, CON(C); Wisdom-Gilliam, Pauline, BSc: Nutrition screening and assessment of risk in patients with gastro-intestinal cancer.

Genna, Margaret, RN, CON(C); Dorion, Maureen, RN, CON(C); Ross, Pamela, RN: The development and implementation of an electronic tool to facilitate communication between nurses in a regional cancer centre and nurses within the community.

Ghesquiere, Fran, RN, BSc, CON(C): An examination of a patient education programme: 'Feeling Your Best.'

Gravelle, Deborah, RN, BScN: Rapid palliative therapy program: Is there a role for nursing?

Gravelle, Deborah, RN, BScN: New roles for nurses in the next century: Whom does a nurse navigator navigate?

Hills, Miriam R., RN, BScN, CON(C): A tapestry of caring: Little things mean a lot.

Hilton, Ann, RN, PhD; Gustavson, Kris, RN, BSN: Children's perspectives on coping with their mother's breast cancer and chemotherapy situation.

Horlin, Rosemary, RN, BScN; Potter, Pam, RN, BScN; Mercer, Neena, RN, BScN; McCarthy, Patricia, RN, MSc(A); Quintenar, Gerardo, BA(Ph), PhD(Th): The role of spirituality in the care of paediatric oncology patients, families and staff.

Howell, Doris, RN, MScN; Fitch, Margaret, RN, PhD; Caldwell, Brenda, RN, BScN: Oncology nurse: Anchor in the wind.

Jahraus, Diane, RN, BScN; Sokolosky, Shirley, RN, BN: Evaluation of the educational program for breast cancer patients receiving radiation therapy.

Johnson, Beverley, RN, OCN: Prostate cancer resource centre provides men with knowledge, support and empowerment.

Jolicoeur, Lynne, RN, BScN, CON(C); Faught, Dr. W., MD, FRCSC: Managing bowel obstruction in ovarian cancer using a percutaneous endoscopic gastrostomy tube.

Kilpatrick, Marilyn, RN; Toews, Sheila, MEd: Weaving the fabric: Designing a rural oncology nursing course.

Kiteley, Cathy, RN, MSc, CON(C); Kooning, Dawn, RN, CON(C); Tozer, Helen, RN, CON(C); Rogers, Beverley, RN, CON(C); DeHay-Turner, Shelly, RN, MScN; Corrigan, Yolanda, RN; Morrison, Maureen, RN, CON(C): Weaving good health through education.

Lachance, Margaux, RN, CON(C): Your genetic test results are ready - Is that the final answer?

Lemonde, Manon, inf. PhD: Rôles de l'infirmière clinicienne spécialiste en oncologie.

MacDonald, Catherine Ann, RN, BSN: The experience of young adult women undergoing hormone replacement therapy after childhood cancer.

Macdonald, Deborah, BSc, RN, CON(C); Veenema, Carole, RN; Kiteley, Cathy, RN, MSc, CON(C); Hesketh, Linda, RN, BA, CON(C); DeHay Turner, Shelly, RN, MScA; Lulham, Kathryn, RN, CON(C): The tapestry was always there: We just wove a new pattern.

MacDonald, Donald, RN, OCN, CON(C); Patterson, Mary Anne, RN, CON(C); Cudmore, Patricia, RN, CON(C): Primary nursing: The continuous thread in the tapestry of care.

Mayer, Judy, RN; Cassidy, Marilyn, RN, BA; Drybrough, Karen, RN, MScN; Lightfoot, Elaine, RN; Nichole, Liz, RN; O'Halloran, Claire, RN: School and the child with cancer: A critical connection.

McCullum, Mary, RN, BSN, CON(C); Bottonoff, Joan L., RN, PhD; Ratner, Pamela A., RN, PhD; Chalmers, Karen, RN, PhD; Buxton, Jane, MBBS, MHSc; Hack, Tom, PhD; Balneaves, Lynda, RN, PhD(c): Genetic testing for breast cancer risk: Women's perceptions & information needs.

McDermid, Anne, RN, MScA, ACNP; Armstrong, Christine, RN, MScN, ACNP: The acute care CNS/NP in paediatric oncology: The continuum of care for the neuroblastoma patient.

CANO Conference 2000 - presenters

McIntosh, Ann, RN, BSN; Rizzo, Virginia, RN: Face to face with technology: Implications for nursing practice.

McQuestion, Maureen, RN, BScN, CON(C); Cheng, T., MSW, CSW; Jackman, M., MSW, CSW; Mulcahy, V., RN, MSc, CON(C): The tapestry of psychosocial care: A patient information package & information organizer.

Mings, Deborah, RN, MHSc, OCN; Fitch, Margaret, RN, PhD; Sevean, Pat, RN, OCN, HBScN, MN, MEd: Challenges facing oncology nursing in Ontario: Making the most out of nursing roles and resources.

Murdoch, Gloria, RN, MScN, CON(C); Doyle, Cathy, RN, CON(C): Weaving ambulatory care into an inpatient blood and marrow transplant program.

Murdoch, Gloria, RN, MScN, CON(C): Infusion cryopreserved bone marrow/peripheral stem cells: Outcomes of infusing washed vs. unwashed product.

Musso, Karin, RN, BSN, CON(C); Berthelet, Eric, MD, FRCPC(c), DipABR; Grant, Vicky, RTT; Ross, Brenda, RN, BSN, CON(C); Yearwood, Linda, RN, MSN, CON(C): Radiation patients need skin assessment

STAT: Pilot study of a skin toxicity assessment tool.

O'Brien, Laurie Anne, RN, BN: "What I knew then and I know now" A journey through 21 years of palliative care.

O'Connor, Carreen, RN, BScN; Bakker, Debra, RN, PhD; Bennett, Jennifer, RN, BScN; Fitch, Margaret, RN, PhD: Instrument development: Nurses' attitudes, subjective norms and behavioural intentions toward cancer-related fatigue management.

Olson, Karin; Baker, P.; Eades, M.; Fitch, M.; Gue, D.; Hamilton, J.; Hanson, J.; Janes, K.; Johnson, C.; Plummer, H.; Stacey, D.: Establishment of the reliability and validity of the WCCNR stomatitis staging system.

Ord-Lawson, Susan, RN, MSc, CON(C); Martin, Allison, RN, MScN; Vaitekunas, Dorothy, RN, BScN: The silent profession.

Page, Beverley, RN, BScN, CON(C); Leahey, Angela, RN, BScN: The challenges of preparing inexperienced nurses to practice in the specialty of oncology.

Painter, Vivian, G., RN, MN: The power of story: Using reflexivity in oncology nursing practice.

Painter, Vivian, G., RN, MN; Fletcher, Karen, RN, BN: Building a dream: Creating an oncology day/evening hospital.

Palmer Wickham, Sherrol, RN, BScN; Page, Beverley, RN, BScN: Measuring nursing across several ambulatory centres: A provincial initiative.

Palmer Wickham, Sherrol, RN, BScN; Kells, David: Workload by exception: Development of an ambulatory workload measurement tool.

Palmer Wickham, Sherrol, RN, BScN; Boudreau, Angela, RN, BScN: "I need to see my nurse right away!" Urgent clinic: An innovative program uniting services to improve quality of care.

Pavlin, Margaret, RN, OCN, CON(C): Nurses and chemotherapy: A century of progress.

Pellicciotta, Laura, RN: Stress among oncology nurses: How complementary therapy made a difference.

Quinn, Candace, RN, OCN: An old disease provides new opportunities for oncology nurses.

Richardson, Pat, RN, CON(C): Outpatient transfusion support for acute myelogenous leukemia (AML) patients following induction chemotherapy.

Ross, Brenda, RN, BSN, CON(C); Yearwood, Linda, RN, MSN, CON(C): Matching needs to resources: It's our move!

Ryan, Mary; Olson, Karin, RN, PhD; Gaudet, S., BScN; Rennie, R.; Hanson, J., PhD: Evaluation of no-dressing management strategy for central venous catheter exit sites.

Shobbrook, Cindy, RN, MN: Where is my mommy? Exploring children's needs when a parent dies: Strategies for helping.

Skrutkowski, Myriam, RN, MSc: Monitoring of informed consent in experimental therapy: Implications for nursing.

Skrutkowski, Myriam, RN, MSc: Perceived uncertainty in cancer survivors.

Stacey, Dawn, RN, BScN, OCN and the Patient Education Committee: Creating a first visit information package to meet the information needs of cancer patients referred to a cancer centre.

Stacey, Dawn, RN, BScN, OCN; O'Connor, Annette, RN, PhD; DeGrasse, Cathy, RN, MScN, OCN; Verma, Shailendra, MD, FRCPC: Decision support for women at risk for breast cancer: Creating and testing a prevention decision aid.

Stalker, Pat, RN, BScN, CON(C); Wright Fiona, RN, CON(C): "Ready for the call": Development of a telephone triage protocol in our ambulatory blood and bone marrow transplant program.

Stuckey, Mary Lynn, RN, MScN, CON(C); Lemon, Betty, RD: A multidisciplinary approach results in decreased hospital admissions for head and neck cancer patients receiving radiation.

Stuckey, Mary Lynn, RN, MScN, CON(C); Velji, Karima, RN, MSc, AOCN; Willson, Barbara, RN, MS, CON(C): Radiation oncology nursing program: The first of its kind in Canada.

Stuckey, Mary Lynn, RN, MScN, CON(C); Velji, Karima, RN, MSc, AOCN; Willson, Barbara, RN, MS, CON(C): Creating and implementing a comprehensive radiation oncology nursing education program.

Stutzer, Cynthia A., RN, MS, COPN; Gove, Sharon, MSW: Stringing a story: A bead program for children with cancer.

Tranmer, Joan, RN, PhD; Heyland, Daren, MD, FRCPC; Chenier-Hogan, Nicole, RN, BScN; Korol, Jennifer, RT; Coulson, Kathy, RN, MSc; Squires-Graham, Mae, RN, MScN; Racz, Darilyn, RN: The relationship between fatigue, symptom distress and decisional role in seriously ill hospitalized cancer patients near the end of life.

Velji, Karima, RN, MSc, AOCN; Stuckey, Mary Lynn, RN, MScN, CON(C); Willson, Barbara, RN, MS, CON(C): Evaluating professional practice standards in oncology nursing.

Vincent, Leslie, RN, MScA, CON(C); Galloway, Susan, RN, MScN, CON(C): Shifting perspectives: Educating nurses about the management of symptoms.

Vroom, Ann, RN, CON(C); Gerbis, Bev, RN, CON(C); Hill, Jan, RN, BSN, CON(C): Piecing ambulatory care together with community linkages for post radiation therapy patients: Providing head & neck patients with resources for care, from treatment completion to their first follow-up visit at VICC.

Wasserman, Eleanor, RN, BA: Evolution of an oncology program: Valuing our history.

White, Sheryl, RN, BScN: Healing through the eyes of the innocent.

POSTERS

Alexus, Lillian, RN, MSN: Cancer information service: Past, present and future.

Andersson, Lourdes, RN, MA; Chow, Edward, MD; Wong, Rebecca, MD; Vachon, Mary, RN, PhD; Franssen, Edmee, MSc; Fung, Kin-Wah, MSc; Pach, Beata, MA; Pope, Joan, RN, BScN; Connolly, Ruth, BSc, MRTT; Szumacher, Ewa, MD; Hayter, Charles, MD; Danjoux, Cyril, MD: Patients' understanding of their own illness and expectation of rapid response radiotherapy.

Besser, Marni, RN, BA, CON(C): Symptom management of patients receiving stereotactic radiosurgery.

Bottorff, Joan L., RN, PhD; Balneaves, Lynda, RN, PhD(c); Grewal, Suki, RN, MSN; Sent, Lorna, MB, ChB; Browne, Annette, RN, MSN: Addressing cultural diversity in cervical screening: Challenges and lessons learned.

Chui, Debbie, RN, MSc: Cancer-related fatigue and patient self-selected fatigue interventions.

Dao, Kim-Nga, RN, BScN, CON(C); Servais, Manon, RN, BSc; Swidzinski, Marika, RN, BA, CON(C): Monoclonal antibodies: The future is now.

Hesketh, Linda, RN, BA Soc, CON(C); Kiteley, Cathy, RN, MSc, CON(C); McKone,

CANO Conference 2000 - presenters

Marcelin, RN; Pirro, Sylvie, RN, BScN: One ounce of prevention reduces constipation.

Landry, Roch, RN: Créer une nouvelle maille: Un nouveau rôle infirmier/ère pour promouvoir la continuité des soins aux patients en radio-oncologie.

Legacy, Marie-Claude, RN, BA: To tell or not to tell?

McGregor, Margie, RN, CON(C); Taylor, Dianne, RN, CON(C); Birch, Wendy, RN, CON(C): "Helping the pieces fit": The role of the primary nurse in patient teaching for chemotherapy.

McGregor, Margie, RN, CON(C); Taylor, Dianne, RN, CON(C); Birch, Wendy, RN, CON(C): "The weave of knowledge" - Introducing the novice nurse to chemotherapy administration by the expert chemotherapy nurse.

Moore, Krystyna, RN, CON(C), OCN; Gilhooly, Kate, RN, OCN: Weaving a pathway to knowledge by sharing the experiences of novice to seasoned radiation oncology nurses.

Moore, Krystyna, RN, CON(C), OCN; Pringle, Nancy, RN: Empowering the patient newly diagnosed with lymphoma: Development of an on-site lymphoma resource centre.

Neithercut, Joanne, RN, BSN; Dorion, Nora, RN, CON(C): A collaborative approach to improving patient education and the cesium experience.

Pellett, Vera, RN, CON(C); Sanfelice, Deborah, RN, OCN; Herman, Ana, RN, OCN; Wright, Janice, RN, MS, AOCN: The transfusion centre spectrum of care.

Ryan, Maureen, RN, BA, BSN, CON(C); Czerkowski, Barbara, MD, FRCPC; Fashanu, Heather, RN; Fyles, Gillian, MD; Hoegler, David, MD, FRCPC; Neelms, Bill, MD, FRCSC: Role of the oncology primary nurse in the early initiation of comprehensive palliative care.

Smith, Jim, RN, OCN; Hylton, Barbara, RN: Integrating g-tube care for patients receiving head and neck radiation.

Stutzer, Cynthia A., RN, MS, CPON; Edna Durbach, EdD: Patient education on-line: From dream to reality.

Tardiff, Linda, RN, CON(C): Inpatient consult nurse: An innovative clinical role.

Tardiff, Linda, RN, CON(C); Cassie, Lynne, RN: High dose rate brachytherapy: A treatment option for breast cancer.

Trewin, Rose, RN, OCN; Fabius, Susan, BSc Pharmacy: Knowledge, training and skill: Create a safe environment when handling cytotoxic agents.

Willson, Barbara, RN, MS, CON(C); Stuckey, Mary Lynn, RN, MScN, CON(C); Velji, Karima, RN, MSc, AOCN: e-Information, e-Learning, e-Communication, e-Easy.

Yearwood, Linda, RN, MSN; Robinson, Carole, RN, PhD; Daniels, Karen, RN; Hill, Jan, RN; Lamont, Sandy, RN; Musso, Karin, RN, BSN; Robertson, Bev, RN; Sundberg, Helen, RN; Upright, Cheryl, RN, MSN: Care of malignant cutaneous wounds: Evaluation and revision of care guidelines.

WORKSHOPS

Brown, Janie, RN, MSN, MA (Psych): Finding peace of mind in the midst of fear, anxiety and loss: The challenge for people with cancer, their families and the oncology nurses who work with them.

Causton, Elizabeth, MSW, RSW: Dancing on the edge: The value of maintaining a therapeutic distance in healing relationships.

Findlay, Barbara, RN, BSN: When your patients choose complementary/alternative therapies (CAM): Exploring issues and shifting roles.

May, Katharyn A., RN, DNSc, FAAN: Demystifying research in practice.

Stutzer, Cynthia A., RN, MS, CPON; Braun, Jane, RN, BSc, LLB; Byron, Patti, RN, BSN; Kerr, Wendy, RN, BSN; Pretula, Angela E., RN, BScN; Van Stolk, Dori, RN, BScN: From diapers to driving: Everything you've always wanted to know about caring for children with cancer and their families.

Syme, Ann, RN, MSN: Clinical skills for the management of advanced cancer. 🌱

Canadian Nurses Foundation/CANO award winners 2000

Congratulations to the following nurses who received the 2000 CNF/CANO awards:

Chris Emery, RN, BSN - 2000 CNF/CANO/Amgen Masters recipient

Chris has been a CANO member for many years and is the past-president of the British Columbia chapter. She currently represents B.C. on the CANO board of directors. Chris is a Master's student in the school of nursing at the University of British Columbia and her work focuses on families.

Doris Howell, RN, MScN - 2000 CNF Doctoral Fellowship in Oncology Nursing

Doris is well-known to many CANO members and, in fact, was president of the organization a few years ago. She is currently pursuing her PhD at the University of Toronto.

The Canadian Nurses Foundation (CNF) is pleased to congratulate this year's CNF Study Awards Program recipients and to announce new partnerships established in support of Canadian nursing. The Year 2000 CNF Study Awards Program has granted 38 awards valued at \$270,850.00. This year marks the creation of the "Aplastic Anemia/Myelodysplasia Nursing Grant" by the Aplastic Anemia Association of Canada in support of nurses with hematology/oncology as their specialty and/or as the focus of their research/studies. This association provides a nation-wide support network for patients, families, and medical professionals, informs the public about aplastic anemia and myelodysplasia, and raises funds for medical research.

The recipient of the inaugural award is **Julie Watson** who is pursuing her Master's degree at the University of Pennsylvania in the pediatric acute care - nurse practitioner program. Julie works with children and their families in a hematology/oncology clinical setting and looks forward to enhancing her skills and knowledge in the advanced practice nursing roles of research, outcome evaluations, and education, in addition to her clinical practice.

Information on the 2001 Study Awards Program is available on the CNF website at www.cna-nurses.ca/cnf or contact Joanna Zito, CNF Scholarship Coordinator, Canadian Nurses Foundation, 50 Driveway, Ottawa ON K2P 1E2. Telephone (613) 237-2159 ext. 286.

CANO Conference 2001



13th Annual CANO Conference

The art of communication: Sharing our stories

CANO 2001 - September 23-26, 2001, Loews le Concorde-Quebec City, Québec

By Andréanne Saucier and Marie de Serres, co-chairs

The theme: **The art of communication: sharing our stories** has guided our planning committee in the organization of the CANO 2001 national conference. We invite you to come and share your stories. Communication is at the heart of nursing practice, research and education. In oncology nursing, the art of communication is found in the therapeutic dialogue that occurs between nurses and people living with cancer and their families. All forms of communication have the potential to shape human experiences and leave meaningful impressions on the individuals and families we encounter. This conference will be the perfect opportunity for

us to communicate and share our stories among ourselves. Plan to attend and mark the conference dates on your calendar.

The program being developed is already very exciting. On Sunday, September 23, 2001, you will be able to choose between eight pre-conference workshops (four each in French and English). In the opening ceremony, the team of Mario Bilodeau, Linda Hershon and Jennifer Crysdale will transport you to a therapeutic experience, a program for teens diagnosed with cancer. Fabie Duhamel, teacher, researcher and family therapist, will present communication with patients' families. During the conference, the stories you share about your professional life (clinical practice, education or research) will enrich our program and we look forward to receiving

your abstracts. In the closing ceremony, a panel of experts, Ann Lynch, associate director of nursing, Ghislaine Desrosiers, president of the Ordre des infirmières et infirmiers du Québec [Order of Nurses of Quebec] and Josée Legault, political columnist for The Gazette, will discuss the art of communication from various perspectives.

During the conference, you will have the opportunity to visit the beautiful city of Québec, with its blend of French and North American cultures. The social events committee has discovered picturesque sites for you to explore. Fall is a wonderful time to visit the region. We look forward to welcoming you to the city of Québec City in 2001. ❀

Conférence de l'ACIO de 2001



13^e conférence annuelle de l'ACIO/CANO

L'art de communiquer : se raconter pour se découvrir

**CANO 2001 - du 23 au 26 septembre 2001,
Loews le Concorde - Québec, Québec**

**Par Andréanne Saucier/
Marie de Serres, coprésidentes**

C'est sous le thème de l' *'Art de communiquer : se raconter pour se découvrir* que le comité organisateur de la conférence nationale de l'ACIO/CANO 2001 vous invite à venir partager vos histoires. La communication est une composante essentielle de la pratique, de la formation et de la recherche en soins infirmiers. En oncologie, l'art de la communication s'exerce et se révèle à travers les mots, les gestes. Elle façonne les relations humaines et s'inscrit, d'une façon toute particulière, dans l'expérience de vie de chacun. Cette conférence se veut un lieu privilégié de communication, de partage et d'échange entre nous. Ne la manquez pas! Inscrivez dès

maintenant les dates à votre agenda.

Le programme que nous bâtissons actuellement s'annonce des plus stimulants. Par exemple, le dimanche 23 septembre 2001, 8 ateliers (4 en français et 4 en anglais) ont déjà été choisis pour cette journée pré-conférence. À l'occasion de la cérémonie d'ouverture, l'équipe de Mario Bilodeau, Linda Hershon et Jennifer Crysdale nous transportera au cœur d'une aventure thérapeutique spécialement conçue pour adolescents atteints de cancer. La communication avec la famille sera également au programme avec Fabie Duhamel, professeure, chercheure et consultante auprès des familles. Tout au long de cette conférence, vos histoires cliniques, d'éducation ou encore de recherche viendront enrichir cette programmation.

Nous attendons donc avec impatience vos résumés de présentation. À la clôture, un panel de discussion réunissant une directrice associée en soins infirmiers, M^{me} Ann Lynch, la présidente de l'Ordre des infirmières et infirmiers du Québec, M^{me} Ghislaine Desrosiers, et une journaliste, M^{me} Josée Legault, abordera l'art de la communication selon différentes perspectives.

De plus, cette conférence vous donnera la chance de visiter l'une des plus belles villes du Canada, à la fois européenne et nord-américaine. Le comité des événements sociaux a découvert pour vous plusieurs endroits charmants de Québec. Vous aurez la chance de voir Québec et ses environs sous leurs plus beaux jours d'automne. Venez fêter avec nous. On vous attend. ❀

CANO/Pharmacia Awards of Excellence Winners 1994-1999

Where are they now?

In 1994, Pharmacia first sponsored awards of excellence for CANO members. The original three areas were practice, education, and research; administration was added in 1996. Over the years, CANO members have benefited from these awards and CANO is grateful for the ongoing support of Pharmacia. At this point in our association, it seems fitting to provide an update on where these winners are now and how they are contributing to oncology nursing.

Practice

Dianne Johnson (1994) is currently a nurse clinician on the pain and symptom management team at the London Regional Cancer Centre in London, Ontario. She is contributing to oncology nursing through many activities. Dianne has been a CON(C) since 1997 and has served CANO in many capacities. She was on the clinical practice committee from 1995-1999, the CONJ review board from 1994-1997, and is currently on the CONJ editorial board. She was also a founding member of the local CANO chapter, and was part of the development group for the CANO/Janssen-Ortho fatigue initiatives and trained as a workshop facilitator.

In collaboration with the primary care team at the cancer centre, the host hospital oncology unit, and care providers in the communities throughout southwestern Ontario, Dianne works as a nurse clinician to apply her knowledge and skills in assessing and managing patients with complex pain and other symptoms related to their cancer diagnosis and treatment. She also practises in a nurse-run lymphedema clinic which was initiated, developed, and staffed by the three nurse clinicians on her team to provide assessment and follow-up for cancer patients experiencing lymphedema secondary to their cancer diagnosis and treatment.

Dianne also manages to find time to lecture on cancer pain in the clinical clerk program for medical students who rotate through the cancer centre, because she believes it enhances collaboration between oncology nurses and physicians. She is on the faculty for the SCOPE (Supportive Care in

Oncology: Partnerships in Education) program which provides opportunities for care providers of all disciplines throughout her region to enhance their knowledge and skills with the goal of sharing this with other care providers in the home communities of their patients. Dianne presents at local and national conferences and is a member of several committees at the cancer centre, as well as being a member of the city-wide London palliative care committee.

When Dianne won her award, one of the nurses at the cancer centre notified the local newspaper (without her knowledge) and told her to read the paper on a specific date. A short profile was published in a column which recognized "outstanding achievements" of local citizens. A local radio station then called her the same day to do an impromptu interview live "on air." Dianne wrote, "This is the total extent of my media attention. Thank goodness the paparazzi never attempted to photograph me for the tabloids!"

Dianne was enthusiastic about her experience of winning the award. She wrote, "I could not believe that I was nominated by peers whom I feel are just as deserving. This just blew me away! This was an honour in itself. I was even more shocked when the CANO committee selected me for the award. It is difficult to express in words all the emotions associated with this event, but it validated and encouraged my personal commitment to strive for excellent nursing care for my patients. Professionally, I think this award opened several doors so that I could contribute in additional ways to oncology nursing. I was approached very soon after receiving the award by CANO members to join the clinical practice committee and the CONJ review board. I also feel that it gave me more credibility as a member of various committees at the cancer centre and in the community. I believe my winning this award created a very positive feeling among my peers at the cancer centre. Oncology nurses relate to each other in a very special way and when a peer is selected for such an award it impacts positively on the group."

"I have always felt that CANO welcomed and nurtured nurses at the 'hands on/staff

nurse level.' This award program reflects that philosophy by including the clinical practice category. I think this award program is a very powerful and positive way to acknowledge the work that represents not only the recipients, but hundreds of oncology nurses across Canada who are involved in administration, education, research, and clinical practice. There are just a few of us who are publicly awarded this honour, but many, many more who are just as deserving."

Helen Creelman (1995) retired in 1997, but continues to be involved in oncology care. For example, she co-authored an oncology nursing article which has recently been submitted for publication. She volunteers on the board of the New Brunswick division of the Canadian Cancer Society and is on its patient services and program committee. She also volunteers with the New Brunswick Breast Cancer Information Partnership and is involved with an evaluation of the information kits developed for newly diagnosed patients with breast cancer. Further, she represents New Brunswick on the Canadian Breast Cancer Initiative Community Capacity Building Committee and also works with new immigrants through the local multicultural association.

Helen wrote, "I was very pleased [to receive the nomination] and felt that if I did earn this award - awesome - I needed to work hard to justify it. I have always felt, and still do, that my work in oncology was a great privilege. I believe the award stimulates and rewards excellence in oncology nursing."

Nancy Doyle (1996) is now a clinical nurse in the medical day/chemo unit at Markham Stouffville Hospital, Ontario where she participates in the total care of patients being actively treated for their cancer.

Nancy noted, "Professionally, it was the highlight of my career to have been nominated for an award of excellence. To have won it was an added honour. We should all take advantage of any opportunity we have to acknowledge our co-workers who have contributed above and beyond in their nursing careers."

CANO/Pharmacia Awards of Excellence

Liz Nichol (1997) is in community-based nursing practice and provides care to children with cancer and their families through the Interlink Community Cancer Nurses and the Hospital for Sick Children.



She is committed to strengthening and refining her nursing practice by seeking opportunities to further assist families and by contributing to the growth of the pediatric team.

Following the announcement of her award, Liz "received congratulations from many colleagues and members of the childhood cancer community. This award was tremendously meaningful as it came toward the end of my professional career. I was surprised, humbled, and altogether thrilled by the recognition."

Linda Masko

(1998) works as a staff nurse in the emergency department of West Nipissing General Hospital in Sturgeon Falls, and she is a train-the-trainer nurse in the community oncology clinic of the Northeastern



Regional Cancer Centre. She is an active member in CANO and is presently serving her second term as vice-president. Linda actively promotes the specialization of oncology nursing at any and all opportunities to her community, other staff members, and the hospital administration. In collaboration with colleagues, she initiated a systematic assessment of the needs of cancer patients in her community. Utilizing the principles of participatory action research, the process of implementing the needs assessment has harnessed community involvement and support for enhancing the delivery of cancer care. Recommendations from this review resulted in new policy development, significant changes, and improvement in meeting patient, family, and health care provider needs.

Linda was encouraged to continue her work in oncology because of the award. "It validated the work I was doing and helped to increase my passion for oncology nursing. It

also helped to increase my self-confidence and I have gone on to make oncology nursing presentations at the provincial, national, and international level. After 23 years of nursing, this was the first professional award I had received. It was an honour just to have my name submitted and a greater distinction to have won. Outside a large tertiary centre, the work being done by oncology nurses is sometimes not recognized. Receiving this award gave me a true sense of the importance of any work being done to meet the needs of cancer patients and their families. It also helped to increase the confidence of the patients in the abilities of the staff working in our clinic. One has to remember that coming from a small community of 6,000 people versus attending a large regional cancer centre, patients sometimes have concerns regarding the experience and knowledge of the nursing staff in the outreach clinic."

Linda continued, "Promoting professional growth can be a very expensive endeavour. The financial assistance that accompanied this award was also greatly appreciated and helped to fund [my attendance at] the following year's national oncology conference."

Karima Velji (1999) is an advanced practice nurse at the Princess Margaret Hospital, Toronto where she contributes to oncology nursing in five domains of practice: clinical practice, education, research, leadership, and scholarly practice. Karima provides clinical care to patients with complex physical and psychological sequelae from cancer or cancer treatment in an advanced practice, nurse-managed, symptom management clinic. She also provides clinical consultation around complex skin and wound care management. She led the development of the first comprehensive radiation oncology nursing program in Canada which has made significant progress in patient care and nursing practice indicators.

In research, Karima led the development of evidence-based practice in the area of cancer symptom management locally within her hospital and nationally through Cancer Care Ontario and the Registered Nurses Association of Ontario. She is a co-investigator on several research programs that pertain to cancer symptom management and quality of life, and is currently enrolled in the first year of her PhD program in nursing science at the University of Toronto. Karima provides leadership to nurses in radiation oncology and to the advanced practice nursing network at her hospital and has been very actively involved in the CONEP project of CANO. She has also worked with the RNAO to develop the best

practice guidelines for pain management. Finally, she has presented at local, national, and international conferences and has begun to publish in peer-reviewed journals.

As a result of receiving her award, Karima wrote that she was "invited to participate as an opinion leader in oncology in the Opinion Leaders Network of the Canadian Cancer Society. National recognition of expertise has led to more consultations from nurses and physicians outside the institution."

Karima was "personally gratified to be nominated in the category of practice, as it is a basis of all the other work that I do. It was gratifying to be nominated by nurses who I work with and for whom I have a great deal of respect. It was nice to have national validation and recognition for my work. Thanks to CANO and Pharmacia for sponsoring the award, and thank you to the nurses at Princess Margaret Hospital for nominating me."

Education

Marion Stotts (1994) retired from acute care oncology nursing in April 2000 and, although she may do some consulting in the future, she is enjoying retirement and volunteer work just now. However, she remains a member of the CANO Pain Initiative Education Project and is on the selection committee for the Maurice Legault Clinical Oncology Nursing Scholarship.

Marion wrote, "I believe the award increased my sense of responsibility to oncology nursing and brought recognition from my employer and peers in Calgary. It may have contributed to my being awarded another award of excellence. It was a real boost to my confidence both personally and professionally. Appreciation for my expertise, skills, and personal investment as seen by my peers was the highest honour I could be given. I believe it is important to honour the oncology nurses who make an outstanding contribution to oncology nursing. It represents the caring and expertise given to oncology patients every day and it also shows we care for ourselves."

Miriam Hills

(1995) works as coordinator of the cancer education program in continuing nursing education and continuing medical education and professional development at the College of



CANO/Pharmacia Awards of Excellence

Nursing and Medicine, University of Saskatoon. She arranges, coordinates, and teaches at nursing workshops focusing on various cancer topics and palliative care. She continues to include information on new trends and developments in cancer care, using both local speakers and those from other parts of Canada. Marion has successfully written her CON(C) and is assisting other nurses preparing to write in spring 2001. She currently serves on the scientific review committee, biomedical research awards panel, NCIC.

"The recognition of excellence was announced in newsletters of the college of nursing and local health districts, as well as in the Saskatchewan Oncology Nurses' Group Newsletter and the Saskatchewan Registered Nurses Association bulletin. I felt very honoured to receive this award. I was taken completely by surprise at the time. Personally, it made me feel very special at a low point in my life, as I had just experienced the end of a 35-year marriage. Professionally, I received many messages of congratulations from local CANO members and nursing colleagues throughout the province."

Barbara Love (1997 with Denise Bryant-Lukosius)

is an assistant professor at McMaster University. She chairs the pediatric and adult oncology nursing program at McMaster. She is also co-chair with Esther Green of the CONEP committee of CANO. Her research interests lie in the area of hope and she is currently involved in a study looking at the role of hope in the provision of care for children with cancer. Barb is vice-president of the board of directors of the Wellwood Resource Centre in Hamilton, which is a community-based and client-driven centre committed to the development of supportive care programs and resources that enhance the quality of life of people living with and working with cancer.

Barb wrote of her award, "There was a sense of validation for work done. The plaque sits on my desk and on those occasions when it seems that "the well has run dry," I or my colleagues and friends refer to it as a touchstone. It reminds me/us that nurses across this country are with us as we forge forward, that as a team we can make a difference."



"Personally and professionally, it was an enormous honour to be validated for the work and passion that had driven the development of the oncology program at McMaster. So many individuals had contributed their time, energy, and vision, and the award was really for all of those people and the program that they had made a reality."

Barbara Shumeley (1998)

is program director of the Comprehensive Breast Health Program which is a program of the Winnipeg Regional Health Authority. She is active in CANO provincially and nationally, she is on the journal review board, and she has presented education sessions provincially and at the CANO annual conference. Barbara also actively supports, promotes, and recruits members to the association. She is a member of the CANO conference planning committee for Manitoba 2002.

Barbara advises in the Red River Community College Oncology Nurse Certification Course, and offers practicum experience at the Breast Health Centre. She is a member of the Urban Oncology Nurses Council, CancerCare Manitoba, and of the Satellite Research Centre (NCIC), Faculty of Nursing, University of Manitoba where she is the oncology nurse representative on this multidisciplinary research team. Barbara has co-developed and presented research utilization workshops for nurses and other disciplines to promote reading and critical review of research for utilization in the care setting. She has co-sponsored and participated in a wide variety of professional and community capacity building strategies (provincially and nationally) to support and improve breast health/cancer services, information, and support to clients and families through mentoring, working with, and learning from oncology nurses involved in these strategies.

"It was an exciting and rewarding experience to be recognized by national colleagues. In addition, colleagues and friends ensured the award recognition was included in the CANO - Manitoba newsletter, the Manitoba Association of Registered Nurses (MARN) newsletter - NurseScene, and in a *Canadian Nurse* article, "Nurses to Know". Because the education endeavours were supported by oncology nurse colleagues and breast cancer survivors, it offered the



opportunity to acknowledge their support. The award also provided the opportunity to highlight to CANO members the unique breast cancer education initiatives taking place in Manitoba."

Barbara went on to say, "The award also strengthened my commitment to the importance of developing and evaluating client-focused education materials and initiatives. Prior to reproducing a breast health resource for and with input from aboriginal women, funding was sought for evaluation. I also co-authored a proposal and received funding from Health Canada, Breast Cancer Community Capacity Building Initiative to support a collaboration and partnership initiative aimed at improving professional and public awareness of breast health/cancer education materials/strategies. The timing was right - it gave me the resolve and renewed energy to participate in consultations with the Winnipeg Regional Health Authority for the purpose of developing a provincially-funded comprehensive breast health program. I subsequently applied for and was the successful candidate for the program director position responsible for designing, developing, and implementing the proposed comprehensive breast health program for the province. The award acknowledged the breast cancer education intervention that was based on the findings of my Master's in nursing research thesis work. The intervention was the design, development, and implementation of a unique client-focused resource centre for the provision of breast cancer information and support to facilitate clients' desire to participate in treatment decision-making (Breast Cancer Centre of Hope). To first have the opportunity to implement the findings of one's research and then to have it recognized by a national oncology nursing organization is indeed rewarding."

"On a personal and practical level, I used the award monies to fund a trip to visit a nursing colleague in Vancouver. This friend and nurse colleague is working on her doctoral studies and during this visit I had the good fortune to actively participate in her personal and professional journey through discussion, debate, paper edits, and mutual commitment to the nursing profession. I would like to acknowledge and thank Pharmacia for their initiation of this award and for their ongoing commitment and sponsorship. This award is a symbolic act of both recognition and "caring" for a professional group of nurses who are the traditional givers of 'care' - a unique and special gift."

CANO/Pharmacia Awards of Excellence

Karen Tamlyn (1999) is currently a professor and assistant dean of BN programs in the Faculty of Nursing, University of New Brunswick, Fredericton, NB. She teaches the specialty content related to oncology



nursing in the basic four-year program at UNB. She also works with graduate students in the MN program offered at UNB who are studying in areas relating to oncology nursing. She continues to co-teach a three-credit, web-supported oncology nursing elective to undergraduate students in their senior year. Karen is a member of a research team developing a research proposal to investigate the impact of prostate cancer on men's sexual functioning.

Karen commented, "I feel very privileged to have even been nominated for this award by my peers in New Brunswick. Winning the award meant a great deal to me both personally and professionally. When I came back to my workplace after the conference, my colleagues had made a big banner of "congratulations" and put it on my office door. I know how busy all of our lives are, and I know how much time and effort it takes to put all of the information together to submit for these awards (because I nominated someone the year before). Historically in our profession, I do not think we have done a good job of honouring, promoting, and perhaps even valuing our own members. I feel this is one very visible way oncology nurses accomplish this in Canada. I feel very honoured to be on this list with so many leaders in oncology nursing in Canada!"

Research

Karin Olson (1994) is a research scientist who is completing a fellowship in palliative care and qualitative methods at the International Institute for Qualitative Methodology at the University of Alberta. Her research program focuses on fatigue in cancer and palliative care as well as five other populations.

Karen noted, "Winning the award was a tremendous honour. It came at a time when our research program was just starting to gather momentum. It felt to me like the cancer nurses of Canada were saying, 'you are headed in the right direction - keep going.'"

Margaret Fitch (1995) is head of oncology nursing and supportive care (TSRCC), co-director psychosocial and behavioural research unit (TSRCC), and co-ordinator supportive care (provincial) (CCO)



Toronto-Sunnybrook Regional Cancer Centre, Cancer Care Ontario. She also has a cross-appointment to the Faculty of Nursing at the University of Toronto. Marg provides leadership for oncology nursing within the institution and at the provincial level. Through her research and subsequent publications/presentations, she is providing evidence upon which oncology nurses can base their practice. She also provides leadership for oncology nursing at an international level through her volunteer professional activities.

"At a personal level, I was honoured to have been nominated and selected for the award, especially by my peers. I was able to share the announcement about the award and it helped with the profile I was establishing as a researcher in my facility."

Monica Bacon (1997) is a clinical trials coordinator and is "still stimulatedly working at the NCIC Clinical Trials Group at Queens University in Kingston, a worksite with constant challenges and opportunities to learn and grow." She holds



many positions, such as coordinator of the NCIC CTG gynecancer committee including the cervix cancer working group, the endometrial cancer working group, and the ovarian cancer task force; secretary-treasurer for executive board of COS (federation of Canadian Oncology Societies); secretariat of GCIG (Gynecologic Cancer International Intergroup); member of NCI US gynecancer common data elements committee; member of common toxicity criteria working group; and member of NCI US surgical complications working group - common toxicity criteria. Monica uses her oncology experience and expertise in all she does. As a study coordinator, she has continuous contact with oncology nurses across Canada as well as interna-

tionally and "collaboration is the name of my game." As often as possible, she highlights or brings the focus to nursing-related issues in the world of cancer clinical trials.

Monica is founder and coordinator of the Canadian Clinical Trials Nurses (CTN) Special Interest Group (SIG) which numbers about 150 members. This SIG has published and presented broadly and made successful efforts to raise the profile of CTNs. As CTN SIG coordinator, she is a member of the CANO research committee where she is ever alert for CTN and nurse researcher collaborative efforts. She is a co-editor of the recently published (January 2000) **ONS CTN Manual for Education and Practice** and is delighted that her association with this book enabled an international section in the manual. Continued collaboration between the Canadian and American CTN SIGs is evident in a current joint research project on roles and responsibilities of CTNs, as well as in discussions towards a joint educational session at the next ISNCC conference (2002).

Monica noted, "As well as an abundance of well wishes, my colleagues at NCIC CTG held a surprise, congratulatory tea party for me. The award was a definite boost to me personally and professionally as far as my self-confidence and self-esteem. There was a true sense of pride in the recognition of my oncology nursing and other colleagues. Some of the quotes from my nominees were not only a surprise but an honour, never to be forgotten. I also hope that I serve(d) as a role model for other oncology nurses in that perseverance, hard work, and collegiality can be as rewarding as credentials.

Donna Green (1998) is a clinical trials coordinator at the Dr. H. Bliss Murphy Cancer Centre, St. John's, NF. As clinical trial coordinator, she has increased awareness of the clinical research being conducted at her centre, the importance of doing this research, and the role of the oncology nurse in ensuring the trials are done ethically.

"Personally, winning the award gave me a lot of gratification. It certainly confirmed to me that all the hard work I put into developing the clinical trials program was well worth it. I felt very proud. Professionally, I feel that winning the award has increased my profile within my workplace. Our cancer centre put a note of congratulations in our local newspaper, as they felt it was certainly an achievement for both me and our centre (as they have always been very supportive of my work). It let the public know that we are running a centre of excellence, including oncology clinical research.

CANO/Pharmacia Awards of Excellence

Ann Hilton

(1999) is a professor in the UBC School of Nursing. She is currently on the board of directors of the International Society of Nurses in Cancer Care and chairs the ISNCC research committee. She is also on the board of directors of the Canadian Association of Psychosocial Oncology and chairs the membership committee. Ann has contributed to CANO in many ways. She has offered several two- and half-day program evaluation workshops, given input and consultation related to the education initiative and other initiatives, she just came off the editorial board as associate editor for research for CONJ, she was on the advisory board re the fatigue initiative, and was on the research committee for several years as member and chair and as chair of the evaluation committee. Ann has done research related to individual and family coping with cancer, as well as evaluation of programs such as the fatigue initiative.

A number of announcements went out in Ann's province about the award and she received a letter from the UBC president and dean about it. Ann wrote, "I have always highly respected CANO as an organization and it is because it is composed of nurses who are strongly committed to promote positive changes for patients and their families with cancer. Each member offers so much and in their own way, and is willing to share their expertise. Over the past many years, I have had the opportunity and pleasure to work with a number of CANO members in various ways. I have always held the CANO Awards for Excellence in very high regard. I was therefore particularly thrilled and honoured to be selected for the Award for Excellence in Research. It means a great deal to me, both personally and professionally, and I cannot possibly express the extent of my gratitude for this recognition. Of the awards I have been fortunate to receive, this award has touched me the most. Being recognized by CANO members for my work related to research was very important to me and being recognized by nurses who represent many areas of oncology: clinical practice, administration, research, and education, made it even more significant and special. For me, this recognition reflected interest, support, and respect for the research I do and for the work I do with others related to teaching about research, writing about research, and actually doing research. Thank you so much.



Administration

Esther Green

(1996) is an oncology nurse consultant, symptom management coordinator program at Janssen-Ortho Inc. The symptom management coordinator program is unique in that nursing positions have been developed in 11 cancer centres across the country to focus on cancer and treatment related symptoms, such as fatigue, pain, breathlessness, and anemia. The prime domains of the positions are clinical practice; education of patients, their families, and other health professionals; and research. Esther has also been involved in an initiative proposed by the Ministry of Health in Ontario, working in partnership with McMaster University to develop a strategic plan to support oncology nursing education. This proposal is led by Barbara Love at McMaster University, and is in concert with the CANO oncology nursing education project. Esther co-leads CONEP with Barbara Love and works with oncology nurses from across the country on this initiative which is one of CANO's strategic directions. She is also an associate editor, CONJ and president-elect of CANO.

Esther commented, "Receiving the award was a life-altering experience for me. The recognition of my peers and colleagues by way of the nomination was an honour alone. The award came at a time of great change, not only in my professional career, but also in my personal life. In many ways, it has driven me more to dedicate myself to the specialty of oncology nursing, to see beyond the "horizon" and work towards creating ways that we, as nurses, can improve the care for people with cancer and their families. Nurses are humble about the contributions that they make to individuals, groups, and communities. We are often reluctant to talk about or take credit for our accomplishments. I have often asked nurses to describe their successes, when they made significant differences in the lives of others. But the response is usually that it is inherent in the work that they do, and they are modest about their accomplishments. The Pharmacia Awards allow us to recognize the quiet heroines in oncology nursing. Thankfully, we have the support to continue to do this.



Leslie Vincent

(1997) is vice-president, nursing at Mount Sinai Hospital in Toronto. She actively participates in CANO, especially through presentations at conferences. Leslie was a recipient of the Helene Hudson lectureship award. She supports specialization in her institution, including oncology nursing and in 2000 her workplace won the CNA employer award for support of certification. Leslie has an active appointment at the University of Toronto as an assistant professor. She teaches a course on common responses to illness with a focus on the assessment and management of symptoms. She uses her knowledge regarding symptoms and particularly fatigue as a focus for the course.

"It has been very rewarding on a personal level to me. It was a very special award for me. It was a wonderful acknowledgement of my contribution to nursing and the specialty of oncology nursing. The fact that it was awarded by my peers in the specialty means a great deal to me, as these are colleagues for whom I have a great deal of respect."

Barbara McDermott

(1998) works as patient care clinical services coordinator at the BCCA, Vancouver Cancer Centre. A major focus of her position is to recruit nurses to the specialty of oncology and then to support and develop strategies for retention, specifically around resources for continuing education and preparation for CON(C). Professionally, she is actively involved in CANO, BCONG, and RNABC, both as a past member of the executive and particularly in organizing educational events. She also partners with industry to organize local educational events.

Barb wrote, "There was a large reception in my workplace to celebrate the award, an article was written in our newsletter outlining my career and the contributions I had made to patient care and oncology nursing. The article was also



CANO/Pharmacia Awards of Excellence

published in two local newspapers. I was overwhelmed that I had been nominated and felt great pride because the award was supported by my peers and colleagues for whom I have great respect. It certainly was a highlight in my career. I would encourage CANO to continue with the awards and suggest the executive review the process of nomination and selection to ensure it is as accessible as possible to all members.

Jean MacPhee (1999) is director of cancer care services at the Cape Breton Cancer Centre, Sydney, Nova Scotia. She strives to ensure that all staff caring for cancer patients are skilled and certified in oncology nursing according to CANO standards. Jean has developed a chemotherapy program for nurses who care for cancer patients in the inpatient settings. She promotes continuing education and national certification for oncology nurses, and acts as an invigilator for courses and examinations for nurses pursuing oncology nursing through distance education.

Jean commented that, "Acknowledgement of my accomplishment by patients, staff members, peers, formal recognition from senior management" were all important to her. Personally and professionally, she noted that receiving the award was "Rewarding! The award validated that I had worked hard on behalf of the cancer patients in the community and that I had promoted oncology nursing to where it is now recognized as a specialty in this region. I would like to thank CANO and Pharmacia for this award."

Other winners who were unable to respond before the deadline: **Carreen O'Connor** (1996, education); **Lorna Butler** (1996, research).

A final word from Pharmacia Oncology, Paul McCabe, Director

We are thrilled at the positive impact the CANO/Pharmacia Awards of Excellence have made on the lives of so many capable people - the winners, their colleagues, and indirectly, cancer patients across Canada. Thinking back to 1994 and the world of oncology, we truly have come a long way. Yet as we enter 2001, I can't help but think that we have still a long way to go. Recognizing excellence in nursing practice, nursing education, nursing research, and nursing administration is Pharmacia Oncology's way of supporting and encouraging you and your colleagues to excel in a very important profession. We thank you for your tireless efforts. Congratulations to the past winners and best wishes to all in the future. ✦

PHARMACIA Oncology

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: Ms. Monika Dixon;
Tel: 416-961-7223 ext 5673
Email: mdixon@cancer.ca

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Publication dates Submission dates

May 1 December 30
August 1 March 30
November 1 June 30
February 1 September 30

Dates de publication

le 1^{er} mai

le 1^{er} août

le 1^{er} novembre

le 1^{er} février

Dates de réception

le 30 décembre

le 30 mars

le 30 juin

le 30 septembre

March 2-3, 2001

Women and Cancer: Myths and Realities.

Multidisciplinary conference. The Westin Bayshore, Vancouver, BC.

For further information contact: (604) 822-0051, fax (604) 822-4835,

rachel@cehs.ubc.ca

March 28-April 1, 2001

“Creating Intimacy” Exploring Boundaries and Frontiers in Death, Dying and Bereavement.

Twenty-third annual conference of the Association for Death, Education, and Counseling. Sheraton Centre Hotel, Toronto, ON.

• Fees: US\$330 member, US\$420 non-member.

Contact: ADEC 2001 Conference, 342 North Main St., West Hartford, CT 06117-2507, USA, (519) 745-2195, fax (860) 586-7550, www.adec.org

April 13, 2001

The Canadian Cancer Society Short-Term Clinical Oncology Training Program for Health Care Professionals in Canada. Spring cycle.

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 22-24, 2001

Palliative Care...Weaving the Science Into Art.

Eleventh annual palliative care conference. Royal York Hotel, Toronto, ON.

• Fees: \$395 member, \$450 non-member. Contact: Teresa Sottile,

Conference Manager, Humber College, Corporate & Continuing Education,

205 Humber College Blvd., Toronto, ON M9W 5L7, (416) 675-6622 ext. 4559,

fax (416) 675-0135, sottile@admin.humberc.on.ca

May 17-20, 2001

Twenty-sixth Annual Oncology Nursing Society Congress, San Diego, CA.

Contact: Pearl Moore, ONS, Pittsburgh, PA. Fax (412) 921-6565, member@ons.org

June 24-27, 2001

Facing the Challenge Together. Third global conference for cancer organisations.

Brighton Centre, Brighton, UK.

Contact: request information by fax +44 20 8743 1010, www.globalcancerconf.com

September 20-21, 2001

Living the Transitions. Eleventh annual provincial hospice

palliative care conference. Winnipeg Convention Centre, Winnipeg, MB.

Contact: Pat Maruca, Hospice and Palliative Care Manitoba,

2109 Portage Avenue, Winnipeg MB R3J 0L3, (204) 889-8525, fax (204) 888-8874,

pmaruca@manitobahospice.mb.ca

September 23-26, 2001

L'art de communiquer : se raconter pour se découvrir /

The Art of Communication: Sharing Our Stories.

Thirteenth annual CANO conference. Loews Le Concorde Hotel, Quebec City, PQ.

Contact: CANO Office, 329 March Road, Box 11, Suite 232, Kanata, ON K2K 2E1,

(613) 270-0711, fax (613) 599-7027, canoacio@igs.net

October 13, 2001

The Canadian Cancer Society Short-Term Clinical Oncology Training Program for Health Care Professionals in Canada. Fall cycle.

Contact: Monica Dixon, CCS (National), 10 Alcorn Avenue, Suite 200,

Toronto, ON M4V 3B1. (416) 934-5673, fax (416) 961-4189, mdixon@cancer.ca

November 9-11, 2001

ONS Fall Institute, St. Louis, Missouri. Contact: Pearl Moore, ONS, Pittsburgh, PA.

Fax (412) 921-6565, member@ons.org

November 15, 2001

The Maurice Legault Fellowship for Registered Nurses.

Contact: Monica Dixon, CCS (National), 10 Alcorn Avenue, Suite 200, Toronto, ON M4V 3B1.

(416) 934-5673, fax (416) 961-4189, mdixon@cancer.ca

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

Materials on Review *Critique des nouveautés*

Consumers guide to cancer drugs

Authors Gail M. Wilkes, RN, MS, AOCN and Terri Ades, RN, MS, AOCN. Published in 2000. Publisher Jones and Bartlett. 448 pages. ISBN # 0-7637-1170-5. Cost: \$27.95.

Reviewed by Linda Varner

The **Consumers guide to cancer drugs** offers easy-to-understand information about drugs used to treat cancer, as well as drugs used for symptom management in cancer care. It was written for cancer patients and their families. It is divided into two distinct sections: Section One is about cancer treatment drugs and Section Two deals with symptom management drugs. Within each section, drugs are listed alphabetically by generic names. All generic and trade names are listed in the index for easy cross-referencing.

In both sections, each drug has information divided into the following sub-sections:

- **trade name** - the brand name
- **category** - type of drug, i.e. chemotherapy, BMR, antibiotic, etc.
- **classification** - includes its indications
- **action** - describes how the medication works
- **how drug is given?** - includes the routes, when best to take it, and how to store it
- **how should I take this drug?** - this sub-section is for oral medications only. It reminds patients to ask for further directives if they do not understand

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.

- **before taking this drug, notify your doctor of the following** - reminds patients to discuss pre-existing conditions, issues surrounding contraception, the utilization of over-the-counter drugs and herbs and alcohol
- **precautions** - includes drug interactions and major concerns when taking the drug
- **side effects** - classified as more common, less common, and rare
- **side effects/symptoms of this drug** - indicates when to report critical side effects to the doctor or nurse
- **FDA approval status** - indicates whether it is approved in the United States or remains investigational

Information about each drug is limited to two pages and the generic name is always on the left page, making it easy for the reader to have all the information provided at a glance. The sub-sections are clearly highlighted for quick access. The reading level is appropriate for most patients.

Being an American publication, it lists most of the chemotherapy drugs, but some frequently used in Canada are missing, e.g. Epirubicin. Some trade names are different, i.e. epoetin alfa is Epogen or Procrit instead of Eprex. Some are listed as approved by the FDA, but they are not necessarily approved in Canada, e.g. oprelvekin or Neumega. There is an introductory chapter on chemotherapy principles which covers everything from the cell cycle, drug classification, and types of vascular access devices to common and specific side effects of chemotherapy. This might be overwhelming to a lot of patients.

All of the information lines and web sites are American. The Imperial system is used

instead of the metric system which may be confusing to Canadian patients. For example, they may not know when to report a high temperature because it is reported as 100.6° F instead of 38.5° C. The size of the print is very small, making it difficult to read by our aging population.

Certain subsections offer very little information, i.e. "How should I take this drug?" and "Before taking this drug, notify your doctor of any of the following." The information is the same for all the drugs regardless of their classification or action. It warns the patient of possible birth defects, whether the drug is Adriamycin or epoetin alfa, which may be confusing.

The most useful subsections are: "classification; how drug is given; precautions; side effects; and side effects/symptoms of this drug." A lot of investigational drugs are listed. There is a glossary at the end of the book which explains terms in a simple fashion.

Consumers Guide to Cancer Drugs has been written for Americans. The information is well laid-out, but may be confusing unless explained by a health professional. Most of the new drugs appear in it, but information about the side effects is often incomplete. This book may be useful to health care providers who wish to give written information to their patients. It may be useful for oncology nurses as a quick reference and a teaching tool.

Linda Varner, RN, BScN, CON(C), is a clinical resource nurse at the Dr. Léon Richard Oncology Centre, Moncton, NB.

For Enquiring Minds - Le coin des esprits curieux

Decision-making in adolescents being treated for cancer: A grounded theory study

By Jennifer Crysdale, RN, BScN

The purpose of this research study is to discover the process by which adolescents with cancer make decisions regarding their treatment and their everyday life. The specific research question being posed is: How do adolescents, between the ages of 14

and 16 who are being treated for cancer, make everyday life decisions and treatment-related decisions?

The study setting is a large, pediatric, tertiary, academic health science centre within the hematology/oncology program. The participants are adolescents between the ages of 14 and 16 years of age who are being

actively treated for cancer. A grounded theory approach is being used to explore the process of decision-making. Data collection involves one-to-one semi-structured interviews, as well as journals. Analysis follows the procedures of grounded theory. Data are presently being collected with three participants to date.

Jennifer Crysdale, RN, BScN, Hospital for Sick Children in Toronto, is currently working on her Master's degree in nursing.

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

The Ontario Breast Screening Program - Making a difference through screening and early detection

By Linda Stratton and Maureen Brock

Approximately 7,500 Ontario women were diagnosed with breast cancer in the year 2000 and approximately 2,100 will die from the disease. Breast cancer is the most common cancer in Ontario women and the second leading cause of cancer deaths in women.

Many factors may contribute to an increased risk of breast cancer. However, being a woman and increasing age are the major risk factors. Seventy per cent of women diagnosed with breast cancer have no known risk factors at all. This is a surprising statistic for women, many of whom think they need a family history of breast cancer to be at risk. Our best possible protection is screening and early detection.

History of the Ontario Breast Cancer Screening Program

In 1988, a national workshop on reducing deaths from breast cancer in Canada recommended organized screening for women between the ages of 50 to 69. The organized screening program should consist of high-quality mammography and clinical breast examination, along with the teaching of breast self-examination by a specially educated professional every two years.

In 1989, funding was announced by the Ontario Ministry of Health. In 1990, the Ontario Breast Screening Program (OBSP) was initiated as a program of the Ontario Cancer Treatment and Research Foundation

(now known as Cancer Care Ontario [CCO]). The doors of the first centre in the province opened in July 1990 in London, Ontario. By 1996, the program had grown to 21 locations. As of late 2000, 71 sites are now in operation, which means more women in Ontario can obtain high-quality breast screening closer to home than ever before. In northwestern Ontario, a mobile van provides screening as well as diagnostic mammography and clinical breast examination to women who live outside of communities with mammography facilities and who would not normally be eligible for OBSP. The program compares favourably with international standards. Many family doctors in the communities highly support the program, and high levels of client satisfaction have been achieved.

Overview of the program

The mission statement of the Ontario Breast Screening Program (OBSP) is:

"To reduce the mortality from breast cancer by delivering to women 50 years of age and over a comprehensive, organized and evaluated program that is sensitive to women's needs, builds on health promotion behaviours and fosters partnerships with interested groups in the community."

The goal of the program is to screen 325,000 women a year, representing 70% of women aged 50-69 by the year 2010. The program offers a two-view mammogram by a registered mammography technologist, a clinical breast exam (CBE) by a specially

educated nurse examiner (at most sites), and one-on-one instruction and written information on breast self-examination (BSE). The client also receives an automatic two-year recall letter (one year recall for women identified as high risk) inviting her to return for screening. Women greatly appreciate this feature of the program, as it is one less appointment they have to remember to schedule in the future! Both the woman and her physician are informed of screening results. When abnormalities are detected, either by the nurse examiner, the radiologist, or both, suggestions for further assessment are provided to the primary care or referring physician. If the nurse examiner detects an abnormality, the nurse gives an explanation to the client that her result letter will instruct her to contact her primary care physician, even if the mammogram is normal. Screening centres also facilitate appointments for diagnostic imaging upon physician request and obtain follow-up information on reported abnormalities.

Benefits of an organized program

Recruitment: The OBSP reaches out to all women in its target group. Many strategies are employed to address barriers of distance, language, and other problems. Key materials are translated into many languages, special outreach programs promote the program, shuttle buses and a mobile van serve outlying areas, and program staff work closely with family physicians to encourage them to refer directly. Letters of invitation are also sent out to eligible women on behalf of participating family physicians.

Self-referral: Women aged 50 and over are able to refer themselves to the Ontario Breast Screening Program. Many primary care physicians play an active role in encouraging women to call the OBSP for an appointment by sending letters of invitation to their eligible patients. Women are not eligible if they have had breast cancer or breast augmentation (implants), or if they currently have symptoms of breast disease requiring diagnostic work-up. Women may be screened 12 months after their last mammogram.

Recall system: As discussed earlier in this

article, a computer system facilitates the recall of eligible clients on an annual or biennial basis. Women are reminded at each screen that they will receive a recall letter in the mail close to their next screening date.

Result letters: A unique feature of this program is that both the physician and the client receive notification by mail of the screening results. This saves the primary care physicians time notifying their patients of results and the woman is not left wondering what the end result of her screening was. In the event of an abnormal screen, the primary care physician is notified before the client. In many instances, the woman receives a call from her physician before she receives her letter.

Follow-up of abnormalities: For screen-positive women, having access to timely and accurate diagnostic assessment is paramount. A comprehensive screening program must also be able to facilitate assessment for women. Since 1990, the OBSP has operated a comprehensive assessment program at its Hamilton centre. Evaluation shows that this clinic can deliver assessment faster than the usual approach at other centres. The OBSP also has a breast initiative which encourages and assists communities to establish and develop breast assessment pathways.

Quality assurance and quality control: Quality standards for program delivery are carefully monitored by the program. Nurse examiners undergo specialized education, then participate in an annual practice review by the provincial coordinator, nursing or her delegate. Physics consultants monitor the mammography and film processing equipment. The Canadian Association of Radiologists (CAR) mammography accreditation must be achieved by all OBSP centres. This is a requirement of affiliations. Data collection, outcome measurements, film reviews, and chart audits are also included in the extensive quality assurance program.

Evaluation of the program: Outcomes of screening, including assessment outcomes, are carefully monitored. Data are collected and evaluated related to demographics, health practices, risk factors, referral rates, cancer detection rates, assessment procedures, interval cancers, and retention of clients in the program.

Maximum reduction in mortality from breast cancer: To ensure women receive the highest quality screening services as close to home as possible, CCO recently called on all mammography facilities in the province to join the OBSP. As outlined in Cancer Care Ontario's annual report (2000):

The program has set a target of 2010 to achieve the goal of screening 70% of the one million women who should undergo breast screening every two years, or about 350,000 women

annually. When this happens, 500 lives could be saved each year (p.7).

Community outreach programs: OBSP is delivered to communities through partnerships, both formal and informal. Partnerships include hospitals, independent health facilities, family physicians, radiologists, public health nurses, the Canadian Cancer Society, various community groups and services, and volunteers.

Role of the nurse examiner

One of the many unique features of the Ontario Breast Screening Program, as compared to other health care facilities that provide mammograms, is the role of the nurse examiner (NE). As noted earlier in this article, some OBSP sites may not have a nurse examiner. The role is a multifaceted one and interfaces closely with other members of the screening team, primarily the technologists, radiologists, medical coordinators, regional administrators, and provincial coordinator, nursing.

From the moment the woman registers with the receptionist (if not earlier!) for her initial or subsequent screening visit, her anxiety is intensifying. Although the centre is a tastefully decorated, friendly, relaxed environment, women are distracted by their concerns such as, "What will they find?" and "Will this hurt as much as people say it will?" As the nurse examiner greets the woman, she is assessing the woman's anxiety level and making every attempt to ensure that her comfort level, physically and emotionally, is maintained.

Following an explanation of the screening procedure, including results and recall letter, the nurse completes a screening history. The women are reassured the information is confidential and they may choose not to answer a question at any time. The history is brief and the goals are to identify risk factors for women, determine which women are high risk (i.e. annual screen), identify any problems or concerns women are having about their breasts, and ask a question about breast self-examination.

During the clinical breast examination (CBE), the nurse is with the client an average of 15-20 minutes. This provides ample time to teach a client how to thoroughly examine her breasts and answer any questions she may have about her own breast health. The nurse examiner (NE) teaches the woman how to visually inspect her breasts, outlining changes she should look for and report to her physician. The nurse then conducts a thorough examination of supra- and infraclavicular and axillary nodes, teaching the client to do this too. The CBE is then performed with the client sitting upright or standing, lying supine, then followed by the lateral oblique position.

Teaching the client about breast self-examination (BSE) is ongoing throughout the entire examination by the nurse. Norms are described and discussed with each client to familiarize her with her normal breast tissue. This also serves to alleviate anxiety about what she may feel is "abnormal tissue." Many women with nodular tissue are apprehensive about examining their breasts and often state, "I feel lumps all over! I don't know what to look for!" The nurse describes to the client what breast tissue feels like at certain stages in our lives. This is also the springboard utilized by many NEs for stressing the importance of doing a monthly BSE - to "get to know your tissue, not to go lump hunting every month." Women find this is a less threatening approach and they can understand the rationale for "getting to know your breasts so you know what is normal for you." If a woman is very familiar with her tissue, she is more likely to identify a change early. Abnormal findings during the CBE are discussed with the client at that time. She is made aware of the visual and/or palpable area of concern and the need for further assessment and possible work-up.

As a result of the onslaught of information available to women in the media and on the Internet, myths abound. The NE plays an active role in dispelling myths and misconceptions about breast health which often heighten a woman's anxiety level. Women often feel comfortable enough to ask for clarification of the latest information on breast health, correct or otherwise.

The NE has the opportunity, during the CBE, to promote good breast health practices, discuss concerns about the mammogram, stress the importance of regular screening, and promote the mission of the Ontario Breast Screening Program. The nurse communicates specific concerns, fears, or anxieties to the technologist prior to the woman having her mammogram. Together, we work as a team to ensure the woman's experience at the Ontario Breast Screening Program is reassuring, informative, comfortable, and relaxing. In doing so, we have provided an optimal service to the woman that, in the end, may save her life!

About the authors

Linda Stratton, RN, and Maureen Brock, RN, BScN, are nurse examiners with the Ontario Breast Screening Program, London Centre, London, Ontario. Linda was the first nurse examiner hired by OBSP in 1990.

Reference

The Ontario Breast Screening Program (2000). **Annual Report, 1999-2000.** Toronto: Cancer Care Ontario.

PI 1

PI 2

PI 3

Introduction

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Rose G. Steele, RN, PhD, Editor-in-chief
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