
CANADIAN ONCOLOGY NURSING JOURNAL

REVUE CANADIENNE DE SOINS INFIRMIERS EN ONCOLOGIE

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CANADIAN ONCOLOGY NURSING JOURNAL

REVUE CANADIENNE DE SOINS INFIRMIERS EN ONCOLOGIE

Editorial

Another year has passed – where does the journal stand financially?

When I wrote my first editorial in the May 2000 issue of CONJ (Steele, 2000), I tried to make the decision-making processes about the journal as transparent as possible. I noted that despite intense efforts to contain costs, the journal was at risk of running a deficit instead of being at least revenue neutral. I outlined the measures that would be taken to ensure a financially responsible operation.

This editorial provides an update of the past fiscal year.

Streamlining the reporting of revenue and expenses so I can receive updated and accurate financial information has been a major challenge this past year. I need this information to determine how large the journal can be, how much translation we can afford, etc. so CONJ does not run a financial deficit. However, this information has not been readily available and mostly I have had to guesstimate. As you can imagine, this is not ideal. I have tried to err on the side of caution to ensure CONJ does not run into debt, because I want to be fiscally responsible. The downside is that the amount of translation materials may not have been optimized. A new system is now in place which I hope will provide me with the necessary information in a timely manner.

The above information provides a context for examining the CONJ financial statement. I do not yet know if we made a small profit, but I suspect that is the case. I hope you will realize that, although my goal is to run a revenue neutral operation and to maximize the amount of French in the journal, I could not do that very well this year because of circumstances. There is a lot of French in this issue because our advertising revenue increased last month. Advertising is our major source of income, so if you have any potential leads, please let Pappin Communications (heather@pappin.com) know. Further, I encourage you to contact me if you have any questions.

Last but not least, I want to thank the members of the editorial and review boards for their effort, energy, and support. I could not complete all the work of the journal without them.

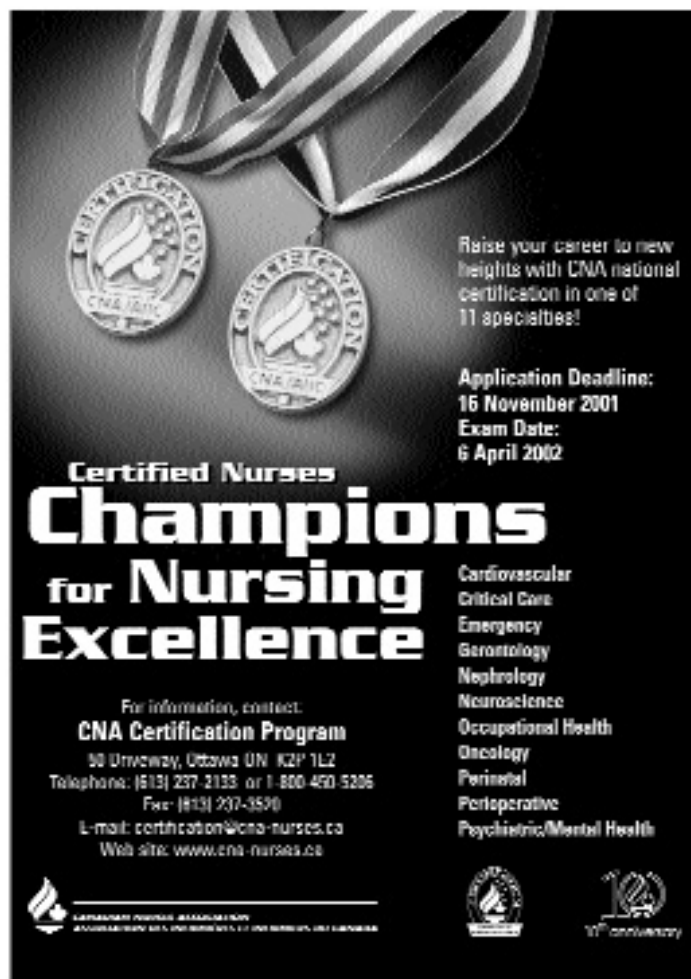
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Steele, R. (2000). Editorial. *Canadian Oncology Nursing Journal*, 10(2), 43.

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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.

A brief introduction to identifying a “good” qualitative study when you see one

by Karin Olson

Canadian nurses who work in cancer care are familiar with research. Our cancer centres are linked together in numerous overlapping cooperative groups that conduct clinical trials. Within our clinical groups, we pride ourselves on having available for interested patients at least one or two clinical trials aimed at improving survival. We have learned to distinguish between “good” clinical trials and trials in which the research methods interfere with the investigator’s ability to answer the questions of interest. In recent years, clinicians have become interested in dimensions of the cancer experience that are not as amenable to study using clinical trials. For example, one may ask, “What does ‘quality of life’ mean to a person diagnosed with recurrent cancer? What role does spirituality play in the lives of women with premenopausal breast cancer? How do patients and their families cope with having cancer? How do patients make treatment decisions?” Qualitative research methods provide ways in which these questions may be explored. The purpose of this article is to provide a brief introduction to ways in which one may identify “good” qualitative research.

Methodological assessment

There are probably as many different sets of standards by which to evaluate qualitative studies as there are people who write in this area. All of these standards, however, share a common commitment to the importance of sound methodology. In order for a qualitative study to be methodologically sound, the research question must drive the selection of the research method, the design of the study must be methodologically consistent, and the conduct of the study must include verification procedures at every step of the research process to ensure rigour (analogous to reliability and validity in quantitative research). Additional readings for qualitative

research are listed in the bibliography.

There are many qualitative research methods. Each method is used to explore a different kind of research question. Individuals interested in an overview of each method are referred to Mayan (2001) and Munhall and Oiler (1986). Of these methods, studies using phenomenology, grounded theory, and ethnography are most common in clinical practice journals and, thus, they form the basis for the remainder of this column.

Phenomenology

Research questions that address the essential nature of an experience, as in the questions above on quality of life and spirituality, are best addressed using phenomenology. Merleau-Ponty (1964) noted that phenomenological analysis provides a vehicle by which one may replace

“habitual concepts, to which we pay no careful attention, by concepts which are consciously clarified and are therefore far less likely to remove us from the experience as it is lived” (p. 61). The sample is comprised of individuals who have experienced the phenomenon of interest and are able to articulate it clearly. The number of participants is determined by the complexity of the phenomenon, but it is often less than 10. The investigator attempts to identify his or her own ideas before beginning data collection and to set them aside (bracketing) so that the voices of participants are heard as loudly as possible. Data are collected through unstructured interviews and participants are often interviewed more than once. The results take the form of an exquisite narrative that describes “the essence” of the experience studied. The phenomenologist gives voice to that which is “taken-for-granted” (van Manen, 1997). Phenomenological research is critically important to nursing practice; it helps us develop concepts that are as close to the experience of patients as possible. These concepts form the building blocks for theories that guide practice.

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Grounded theory

Developed by Glaser and Strauss (1967), grounded theory provides a way to identify the key social processes inherent in interaction and, in this way, build a theory about the interaction "from the ground up." Grounded theory is the qualitative method of choice for seeking answers to questions that involve a process, like those about coping and decision making listed above. The data collection process begins with observation. The researcher must find an environment within which the interactions of interest are taking place. Then, following an initial round of theorizing about the interactions, the investigator identifies and approaches potential participants who appear to know about the interactions, deliberately seeking those with divergent views. This process is labelled theoretical sampling. Data are initially collected through unstructured interviews, with the focus on building a theory rather than a description. As the study progresses and the theoretical shape of the project begins to develop, the investigator may begin to use semi-structured interview techniques, and participants may be interviewed on more than one occasion. The transcripts of the interviews are initially read and coded line by line, using as many codes as necessary to describe the events taking place (open coding). During open coding, investigators frequently stop to write notes (memos) regarding their ideas about the data. One of the hallmarks of grounded theory is the constant comparison of each code with each of the other codes to identify concepts grounded in the data (Glaser, 1978). During this step in the analysis, common threads between codes are identified. These common threads become concepts and the codes become conceptual indicators. New participants are recruited until no new codes are identified and the emerging concepts are sufficiently defined to allow the investigator to see the relationships between them. At this point in the analysis, grounded theorists say the data are saturated. Grounded theory is useful in clinical practice because it helps us build theory that can guide the development of nursing interventions.

Ethnography

Ethnography was initially developed in the late 19th century to study 'other' cultures. More recently, ethnographic methods have been used to study topics of relevance to nursing, such as the culture of the patient care setting. Ethnography is characterized by the immersion of the investigator in the culture being studied. This immersion, termed fieldwork, facilitates the collection of data from multiple sources (e.g., participants, newspaper clippings, field notes) using multiple data collection strategies (e.g., observations, interviews) (Fetterman, 1998).

The objective of ethnography is to create a description of a context within which many concepts and processes exist. Although ethnography is descriptive, it can be differentiated from phenomenology by its breadth. Given this breadth, the investigator may generate both descriptive and exploratory theories of culture from which hypotheses can be identified. For example, Agnes Aamodt and colleagues used ethnography to answer the question, "What cultural knowledge informs the behaviour of children with chemically induced hair loss?" (Aamodt, Grassl-Herweke, Farrell, & Hutter, 1984). The research question guides the way in which the investigator becomes part of the culture and interacts with it. Participants are selected on the basis of their knowledge of the culture and their ability to articulate it clearly. Their job is to teach the investigator about their culture. The investigator becomes the student, seeking new teachers (participants) from whom to learn and with whom to validate perceptions, until the theory is complete. Data collection and analysis proceed simultaneously. Data are coded and sorted to identify patterns and cultural meaning. The integrity of the study is maintained through prolonged periods of fieldwork and the repeated observations of numerous aspects of everyday life.

Common mistakes in trying to apply qualitative methods

The rigorous application of research methods is crucial to the outcome of qualitative studies. Two common mistakes are the incomplete application of a method, seen in studies in which interview data are coded but the conceptual and theoretical work is not completed, and attempts to apply qualitative methods to textual data obtained as part of a quantitative study. Without the conceptual and theoretical phases of the analytic qualitative research process, the reader is left with a "so what?" feeling. The potential contribution to the development of nursing knowledge is lost. Attempts to apply qualitative methods to data obtained from samples in which the theoretical sampling requirements of the method were violated seriously compromise data quality and, thus, threaten the validity of the study findings. Qualitative research methods all require data obtained by articulate informants who are carefully selected on the basis of their ability to explain their views. The data are collected in this way so that they are sufficiently rich to permit the type of analysis required. It is very unlikely that this kind of data could be obtained, for example, from open-ended questions included in a survey distributed to a random sample.

Given these brief descriptions above, it is clear that each qualitative method serves a different purpose. In order for these purposes to be achieved and for the results of the study

to contribute to nursing knowledge, the research question must match the qualitative method selected and the particular rules of the selected method must be followed carefully and in their entirety. ♦

Karin Olson, RN, PhD, is an assistant professor in the faculty of nursing at the University of Alberta and a scientist with the International Institute for Qualitative Methodology, Edmonton, Alberta.

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Cette colonne se penchera sur les questions d'éducation et de pratique qui intéressent la recherche et son application. Notre but est de vous sensibiliser à la recherche afin que vous soyez plus à l'aise avec ce sujet et réalisiez qu'elle peut être conviviale.

Comment reconnaître une “bonne” étude qualitative : une brève introduction

par Karin Olson

Les infirmières canadiennes œuvrant en oncologie sont rompues à l'utilisation de la recherche. Nos centres de oncologie forment de nombreux groupes coopératifs imbriqués qui mènent des essais cliniques. Dans nos groupes cliniques, c'est avec fierté que nous mettons à la disposition des patients intéressés au moins un ou deux essais cliniques ayant pour but d'améliorer la survie. Nous avons appris à faire la distinction entre les “bons” essais cliniques et les essais où les méthodes de recherche entravent la capacité de l'investigateur à répondre aux questions à l'étude.

Ces derniers temps, les cliniciens ont commencé à s'intéresser à des dimensions du vécu du cancer dont l'étude ne peut se faire au moyen d'essais cliniques. Par exemple, on pourra demander “Que veut dire le terme ‘qualité de vie’ pour une personne diagnostiquée d'un cancer récidivant? Quel rôle la spiritualité joue-t-elle dans la vie des femmes prémenopausiques atteintes d'un cancer du sein? Comment les patients et leur famille s'adaptent-ils au cancer? Comment les patients prennent-ils leurs décisions en matière de traitement?” Les méthodes utilisées en recherche qualitative permettent d'explorer ces questions de diverses façons. Cet article est en fait une introduction succincte à la façon dont on s'y prend pour repérer de “bonnes” recherches qualitatives.

Évaluation méthodologique

Il existe probablement autant d'ensembles différents de normes pour l'évaluation des études qualitatives qu'il y a d'auteurs dans ce domaine. Par contre, toutes ces normes ont en commun l'importance qu'elles accordent à la rigueur de la méthodologie. Pour qu'une étude qualitative soit valable du point de vue méthodologique, la question de recherche doit gouverner la sélection de la méthode de recherche, la conception de l'étude doit posséder une cohérence méthodologique et la

conduite de l'étude doit comprendre des mesures de vérification à chaque étape du processus de recherche afin d'en garantir la rigueur (semblable à la fidélité et à la validité de la recherche quantitative). La bibliographie propose des lectures supplémentaires au sujet de la recherche qualitative.

Il existe une foule de méthodes de recherche qualitative. Chaque méthode sert à explorer un type différent de question de recherche. Les lectrices qui aimeraient avoir une vue d'ensemble de chaque méthode pourront consulter Mayan (2001) ainsi que Munhall et Oiler (1986). Parmi ces méthodes, les études qui font appel à la phénoménologie, à la théorie à base empirique et à l'ethnographie sont les plus courantes dans les revues professionnelles de pratique clinique, et c'est donc sur elles que portera le reste de cette rubrique.

Phénoménologie

Pour les questions de recherche qui examinent l'essence d'une expérience, telles que celles portant sur la qualité de vie et la spiritualité ci-dessus, la phénoménologie constitue la meilleure approche. Selon Merleau-Ponty (1964), l'analyse phénoménologique est le véhicule qui sert à remplacer les “concepts habituels, auxquels on ne prête aucune attention particulière, par des concepts qui font l'objet d'une clarification consciente et qui sont donc moins susceptibles de nous écarter de l'expérience lorsqu'elle est vécue” (p. 61). L'échantillon se compose de sujets qui ont vécu le phénomène à l'étude et sont à même de bien articuler leurs pensées. Le nombre de participants dépend de la complexité du phénomène, mais il est souvent inférieur à dix. Le chercheur tente de cerner ses propres idées avant le commencement de la collecte des données et les met de côté de manière à ce que la voix des participants ait la plus grande portée possible. On recueille les données au

moyen d'entrevues non structurés et il arrive souvent que les participants prennent part à plus d'un entretien. Les résultats sont donnés sous la forme de superbes narrations décrivant “l'essence” de l'expérience faisant l'objet de l'étude. Les phénoménologues expriment ce qui est “considéré comme admis” (van Manen, 1997). La recherche phénoménologique est d'une importance critique pour la pratique des soins infirmiers car elle nous permet d'élaborer des concepts qui suivent du plus près possible le vécu des patients. Ces concepts constituent les composantes fondamentales des théories qui guident la pratique.

Théorie à base empirique

Mise au point par Glaser et Strauss (1967), la théorie à base empirique permet de déterminer les principaux processus sociaux inhérents à une interaction et, de ce fait, de bâtir une théorie sur l'interaction “à partir des faits”. La théorie à base empirique est la méthode qualitative que l'on adoptera pour répondre aux questions ayant trait à un processus quelconque, comme celles se rapportant à l'adaptation et à la prise de décision dans la liste ci-dessus. L'observation constitue la première phase de la collecte des données. Le chercheur doit trouver un environnement au sein duquel surviennent les interactions à l'étude. Après l'élaboration des théories préliminaires relatives aux interactions, le chercheur identifie les participants éventuels qui semblent au courant des interactions, communique avec eux en prenant délibérément soin de choisir ceux dont les vues sont divergentes. On donne à ce processus le nom d'échantillonnage théorique. Au départ, les données sont recueillies dans le cadre d'entrevues non structurés afin de bâtir une théorie plutôt qu'une description. À mesure que l'étude avance et que la forme théorique du projet perçoit, le chercheur peut commencer à utiliser des techniques d'entretien semi-dirigé, les participants pouvant prendre part à plusieurs entrevues. La transcription des entrevues est d'abord lue et codée, une ligne à la fois, en faisant appel à autant de codes que nécessaire pour décrire les phénomènes qui ont lieu (codage ouvert). Durant l'activité de codage ouvert, les chercheurs interrompent souvent leur

travail pour rédiger des notes (mémos) sur les idées qui leur viennent à l'esprit. Un des sceaux de la théorie à base empirique est la comparaison constante que l'on fait de chaque code par rapport aux autres codes en vue de dégager les concepts issus des faits (Glaser, 1978). Durant cette phase-ci de l'analyse, on cerne les dénominateurs communs à plusieurs codes. Ces communs dénominateurs se transforment en concepts et les codes en indicateurs conceptuels. On recrute de nouveaux participants jusqu'à ce que l'on ne puisse plus déterminer de nouveaux codes et que les concepts émergents soient suffisamment bien définis pour que le chercheur saisisse les relations qu'ils entretiennent. C'est à ce moment de l'analyse que les experts parlent de saturation des données. La théorie à base empirique a son utilité en pratique clinique parce qu'elle nous aide à bâtir des théories qui peuvent alors orienter l'élaboration d'interventions infirmières.

Ethnographie

Le développement initial de l'ethnographie, à la fin du 19^e siècle, avait pour but l'étude des 'autres' cultures. Plus près de nous, on s'est servi de méthodes ethnographiques pour étudier des sujets d'une grande pertinence pour les soins infirmiers tels que la culture du milieu des soins aux patients. L'ethnographie se caractérise par l'immersion du chercheur dans la culture examinée. Cette immersion, qu'on appelle recherche sur les lieux, facilite la collecte de données en provenance de sources multiples (p. ex. participants, coupures de journaux, notes de terrain) au moyen de stratégies multiples de collecte des données (p. ex. observations, entretiens) (Fetterman, 1998). L'ethnographie vise à créer la description d'un contexte au sein duquel existent de nombreux concepts et processus. Quoique l'ethnographie soit de nature descriptive, elle se démarque de la phénoménologie par son ampleur. Grâce à cette dernière, le chercheur pourra produire des théories à la fois descriptives et exploratoires de la culture qui serviront à dégager des hypothèses. Par exemple, Agnes Aamodt et ses collègues se sont tournés vers l'ethnographie pour répondre à la question, "Quelles connaissances culturelles guident le comportement des enfants atteints d'alopécie d'origine chimique?" (Aamodt, Grassl-Herweke, Farrell et Hutter, 1984). La question de recherche oriente la manière dont le chercheur s'intègre à la culture étudiée et les interactions qu'il entretient avec elle. On sélectionne les participants en fonction de leur connaissance de la culture et de la clarté de l'articulation qu'ils peuvent en

faire. Il leur revient d'informer le chercheur sur leur propre culture. Le chercheur se fait disciple et est en quête de nouveaux maîtres (participants) auprès desquels il pourra apprendre et valider ses perceptions jusqu'à ce que la théorie soit complète. La collecte et l'analyse des données se déroulent simultanément. On code et on trie les données en vue de dégager des schémas et une signification culturelle. On maintient l'intégrité de l'étude en effectuant des recherches sur les lieux sur une période étendue et des observations répétées de nombreux aspects de la vie quotidienne.

Erreurs courantes dans l'application des méthodes qualitatives

L'application rigoureuse des méthodes de recherche est un élément critique du résultat des études qualitatives. Deux erreurs courantes consistent à faire une application incomplète d'une méthode – comme on le constate dans des études où les données d'entretien ont été codées mais les aspects conceptuels et théoriques ont été ignorés – et lorsqu'on essaie d'appliquer des méthodes qualitatives à des données textuelles tirées d'études quantitatives. Sans les phases conceptuelles et théoriques du processus analytique de la recherche qualitative, les lectrices en viennent à se dire "Et alors?". La contribution possible au développement du savoir infirmier est perdue. Les tentatives d'application de méthodes qualitatives à des données obtenues dans le cadre d'échantillons ne respectant pas les exigences théoriques d'échantillonnage compromettent gravement la qualité des données et par conséquent, la validité des résultats des études. Les méthodes de recherche qualitative exigent toutes des données recueillies par des informateurs éloquents sélectionnés avec soin en fonction de leur capacité à expliquer leurs opinions. C'est ainsi qu'il faut recueillir les données afin qu'elles soient d'une richesse suffisante pour appuyer le type d'analyse requis. Par exemple, il est peu probable qu'on puisse obtenir des données de ce genre à partir de questions ouvertes dans une enquête remise à un échantillon aléatoire.

À la lumière des descriptions succinctes présentées ci-dessus, il est évident que chaque méthode qualitative sert un but particulier. Pour que ces méthodes atteignent leur but et pour que les résultats des études contribuent au développement du savoir infirmier, la question de recherche doit correspondre à la méthode qualitative retenue, et les règles particulières de cette dernière doivent être respectées avec minutie et dans leur totalité. ♦

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Weaving for the future: Using rulers and roses

By Betty Davies

Editor's note

This paper was presented as the opening keynote address at the 2000 CANO conference in Victoria, B.C.

When I was invited to give this keynote address, I was asked to focus on the theme of the conference - Weaving tapestries for the future - and more specifically on the concepts of unity, creativity, and vision. I have been reading a lot of leadership literature lately where vision is looked upon as a necessary precondition for success. It is also a precondition for unity and creativity. And so, I will focus on the concept of vision.

Vision

What is the vision that guides us as we weave the tapestry of oncology nursing for this new millennium? What do we mean by vision? Essentially, vision is a mental journey from the known to the unknown, creating the future from a montage of facts, hopes, dreams, dangers, and opportunities. A vision is an image of a possible and desired future state. This image, this vision, may be as vague as a dream or as precise as a goal or mission statement. A vision always refers to a future state, a condition that does not presently exist and has never existed before. Just as the journeys of Canadians listed in a recent Maclean's magazine were said to have inspired the world, such journeys can dictate the success of a profession. And, just as these individuals, such as Terry Fox, adapted their original visions to changing conditions, so must oncology nurses adapt their visions to keep pace with a rapidly changing world.

We all have dreams and fantasies about the future. Most of us picture ourselves more successful, wealthier, and happier than we are now, but we will not reach those goals by idle dreaming. Unlike dreaming or fantasizing, vision helps us to position ourselves and our profession to create and take advantage of future opportunities. Vision is both an offensive and a defensive skill; on the one hand, helping us chart a course that creates changes, and on the other, helping us respond to external changes. Vision is a characteristic of individuals or groups of individuals.

Visionary leaders

Visionary leaders share a common trait - all have a compelling vision and a dream about their work. Clear vision results from a profound understanding of one's organization, of one's profession and

its environment. Vision takes the skill of a craftsman, not a technician. The craftsman can see exactly what work must be done to achieve it. She then puts her tools and materials to work in shaping the product, adjusting and adapting as she goes, keeping in constant mental view the look and feel of the goal. By contrast, if she were to operate as a technician, simply following a set of instructions without vision, a superior product would not result.

One night, the road was bright with the light of an oversized moon. I could not help but pause to admire it, and wonder at the distance between myself and that incredible reminder of space. I wondered at the marvel of having traversed that space, of having found a pathway between here and there, and of putting a man on the moon. I wondered about the vision that guided the journey through space to the moon. All the way home that night, and on many occasions since, the themes of space, vision, and weaving tapestries for the future have wandered in and out of my mind, causing me to think about them at different times, in different ways, and for different reasons.

There are many kinds of space and I imagine that in each of them there is something potentially awesome. There are the spaces between people and the spaces between buildings. There is the space we call time, as well as the space we call distance. And there is the space we know as feeling, interior space. But I suppose the most common of all is the space that is open for our discovery. It is the space through which we will journey toward surprise, disappointment, or simply journey's end. It is strange but true that there are those of us who must try to span space where ever we find it. I know there are some who simply feel they must be on the expansive sea if it's anywhere nearby. There's no way they can stand on the shore for long without finding a boat and getting out into the middle of that space. There are those who climb mountains, partly because it's a space they want to traverse. And, I imagine that in the heart of the explorer, much of what urges onward is a need to fill the voids of space. But haven't you ever wondered what it is that calls, and draws, and urges us to fill those spaces? Haven't you ever wondered why we would leave comfortable situations to venture out into territory that is uncertain and insecure? What is it that calls to the explorer to step out into strange, new, and sometimes hostile territory? What is it that took the explorer from the shore of great oceans to journeys beyond the horizon? A dream? A vision?

Creating vision

How do we develop that kind of vision? It may not always be easy to create powerful vision. New visions often suffer ridicule and laughter, other times they are ignored. That is not to say that one should not create a vision. But there is tremendous effort involved in gaining or creating vision. Most people attempt to develop vision from the circumstances in which they find themselves. In order to generate real vision, however, the vision must be conceived independent of the circumstances. The vision must also be conceived without reference to the apparent possibility or impossibility of its accomplishment. Since most people have been trained to think in terms of responding appropriately to circumstances, the unfortunate policy of limiting what one wants to what seems realistic and possible forms a counter-creative habit. Vision is not asking, "What do you want from the alternatives available?" Instead, vision asks, "What do you want?" It is actually astonishing to discover how little ability many of us have to simply describe what we want to create. And yet, the premier creative act is to conceive what one wants to create.

Real vision is the conceptual image of a result a creator wants to bring into reality. If this vision does not come from an assessment of needs, a definition of the prevailing problems, or an analysis of health care trends, where does it come from? Some people approach vision as if it were a deeply hidden treasure to be discovered and revealed. However, conceiving what you want to create is also not a process of

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revelation. Some people generate "brainstorms" which are designed to blitz through preconceived 'mindsets' with fanciful free associations. But free associations consistently miss the heart of the matter, which is the answer to the very simple question, "What do I want to create?" "What do I want nursing to be?" How one conceives of what one wants is deceptively simple and profoundly sophisticated. Creating a vision takes work, both consciously and unconsciously, but when it comes down to how it is done, the creator simply makes up the vision while thinking, observing, meditating, and pondering. For example, a sheet waving on a clothesline was the beginning of a great balloon, the forerunner of the Zeppelin. A spider web strung across a garden path was the inspiration for the suspension bridge. In their imaginations, creators see what isn't there. Then they start bringing into reality that which never existed before.

Creating visions of desired results is not something we have been encouraged to do. Most people have been trained to focus on method: follow procedures, fill out forms, and adhere to guidelines. These activities answer the question, "How do I bring what I want into reality?" This is a useful question once we know what we want, but a useless question until we do. Most education, however, attempts to train students to consider method first. Take the concept of evidence-based practice, for example. Evidence-based practice is a common theme in professional journals of all health care disciplines. Evidence-based practice is generally characterized as care for a particular disease or condition that is based on scientifically established best practices. In theory, greater use of evidence-based guidelines, particularly those calling for identifying and tracking high-risk patients, would not only cut down on errors within the system, but would result in better population outcomes by bringing in more patients earlier. While evidence-based practice is commonly seen as barely out of its infancy, there is no shortage of protocols, critical pathways, and clinical best practices for everything from expensive coronary bypass surgery to daily, at-home monitoring of patients with asthma and diabetes. The goal is to narrow the gap between what is known and what is practised. Indeed, a worthy goal.

Evidence-based nursing practice and vision

As nurses, we have an obligation to provide the best possible care we can. We have a social and professional responsibility to provide nursing care that is based on sound principles, and that is known to make a difference for patients. Instead of finding out what works by trial and error, or hit and miss, we must provide care based on evidence that what we are doing is safe and promotes patient comfort.

Despite all this, however, I remain a bit skeptical. Perhaps it comes from being in nursing for 30 years now - long enough to have experienced the promised magic of the nursing process, of nursing diagnoses, of nursing theories, and of nursing research itself to provide nursing with the basis for scientific practice for the benefit of patients, and with professionalism for the benefit of the discipline. I am not saying that these aspects have been misdirected, or wrong, or harmful; they are part of the history of the development of nursing, and they have served and continue to serve useful purposes. Each concept caught our collective imagination and carried us to another phase of growth and development.

The nursing process, for example, teaches a problem-solving approach to nursing care. You are all familiar with the four steps - assessment, planning, intervention, and evaluation. When I saw students methodically and systematically following their assessment guidelines, I was impressed with their thorough descriptions of patient situations. But, sometimes, students would follow those guidelines to the letter, without any ability or desire to loosen their hold on guidelines so that they could actually see and hear the person they were assessing. Focusing on information-gathering precluded realizing that the assessment in and of itself was an intervention. HOW a nurse gathers assessment data influences the data that he/she gets. Moreover, as instructors, we emphasized that the nursing

process was not a sequential process, yet we taught the four steps of the process in linear fashion. We didn't practise what we preached. We all know that children and students are alike - they learn much more from how their parents or teachers ACT than from what those authority figures SAY. The nursing process was not a problem in and of itself. The problem lay in conceptualizing complex processes as linear with the result that we focused on procedures and method.

And, herein lies the root of my concern about evidence-based practice. It too lures us into focusing on procedures and methods that provide quantitative evidence of the difference that certain interventions or treatments can make in the lives of patients/clients and their families; evidence that is "scientifically proven." Scientific evidence usually implies a quantitative approach to isolate causes and effects, to operationalize theoretical relationships, and to measure and quantify phenomena (Flick, 1998). Scientific evidence traditionally seeks meaning in numbers - the way of the ruler. It is usually based on a traditional view of "what counts." The Oxford Dictionary (1971) explains that *count* and *compt* were the same words, and they derived from the Latin *computare*. *Com* means *together*, and *putare* means *to think*. To count then means *to come together to think*. *What counts* involves the connecting of one human being with another to find shared meanings, not counting numbers. *What counts* is realizing that we have touched someone and that they have touched us. *What counts* to the dying woman is leaving a legacy of love for her new grandson by finishing the afghan she has woven for him.

We must find alternate approaches to finding evidence for *what counts*, especially since many of the obstacles to providing optimal care are not clinical in the traditional sense. Many are structural - like not having enough nurses to provide even basic nursing care. Solving these problems will require efforts far beyond the development of evidence-based protocols, beyond the development of instruments to measure differences in outcome.

Standing on the shore of the polluted and turbulent waters of health care systems, what makes us want to venture forth into this unknown space? What gives us hope and faith in believing that things will improve? Our vision. Our vision of what nursing can be. That's what keeps us going - even if sometimes it's only a faint candle's glow. In Alberta winters, my father always carried a candle in the car because the warmth of a single candle can keep a person from freezing to death. We must remember that it is not the light, but the warmth that sustains us.

Nursing and technology

In today's world, the warmth that nursing offers is threatened by the abundance of technology. Technologies have powerful consequences that are not neutral, but are both good and bad. I had the honour of serving as the president of the Canadian Nurses Foundation (CNF) during its 25th anniversary year. In tribute to this occasion, we conducted a financial campaign to raise funds that would ensure the viability of CNF. Our slogan was "High touch, high tech." This phrase captured our view that as the health care system was becoming more high tech, nursing continued to promote not only the high tech aspects of health care, but also continued to promote the high touch aspects.

What is high tech? Menu, mouse, web, net, Internet. Backup, virus, merge, purge, surge, connected, wired. Crash, shortcut, overload, shut down, back up. High tech is machinery, equipment, computer screens, monitor screens, and TV screens. High tech is a blood transfusion, an amputation, BMT, and prostheses. High tech is the genome project. High tech is innovation, progress, control, future advancements.

What is high touch? It's the love for a child, it's taking the arm of your mother as she steps off the curb because you notice that she's not as steady on her feet as she used to be, it's the sound of your lover's voice on the phone, it's the smell of homemade bread in the kitchen, it's the pink and purple sky of the setting sun, it's the awe of looking up at the mountains, it's the moment of shared laughter between children and grandparents. It's the tear in the eye of your patient who

has just been told her biopsy is negative, it's the hand on the shoulder of your next patient whose biopsy results are positive. It's the daughter's gentle voice that calms the restless old man, it's the quiet moment in the middle of the night when everyone is asleep, it's getting the impossible IV started on your first try. It's listening to the woman sharing her fears for the future, it's overhearing her "I love you" to her dying husband. It's the fresh sheets under the perspiring man with the temp of 40°C, and the gentle breeze blowing in through the open window. It's the look in the eye of your colleague after her patient dies when you say you will take over her patients while she goes for a cup of coffee. It's the feeling of a job well done at the end of the day.

A core feature of my career has been devoted to palliative care for children and families. It has always seemed to me that the core elements of palliative care - responsiveness in all dimensions of life to the whole person, to families, as well as individuals known as patients - more closely realizes my vision of nursing than any other experience so far. Palliative care feels good because I get to be the kind of nurse I always wanted to be. I have always considered myself an oncology nurse too. As we envision oncology nursing for the future, I would like to see oncology nursing more like palliative care than like the laying on of technology.

There is no doubt that high tech has enhanced the lives of our patients, promoted better outcomes for patients, and saved considerable nursing time. Think of even those simple glass mercury thermometers, and the time spent cleaning them, sterilizing them, shaking them, and squinting to see the fine silver line. Nostalgically, we tend to remember sitting quietly with the patient while the mercury crept up the glass stem. But did that really happen? Sometimes. But, most of the time, I remember making rounds, putting thermometers in all the patients' mouths, and then repeating rounds to remove the thermometers. Instead of envisioning what nursing should be and can be, we pine for what we think it used to be.

Old-fashioned technologies become reference points for us all. They mark a certain time in our lives, triggering memories. They evoke emotion. High tech has no reference point as yet. High tech holds the hope of an easier life, but it does not provoke memory. Is that when high tech becomes low tech, or more dramatically, is that when high tech becomes high touch?

High tech becomes high touch with longevity and cultural familiarity. Today a wooden shuttle loom warped with yarn is high touch. Four thousand years ago in Assyria and Egypt, the loom was the latest advancement in technology. Today, it's a high touch object in the museum. Let us be sure that nursing itself doesn't become a high touch notation in the museum of health care professions.

This may be our fate if we do not become technologically competent - just as it has for others who have not kept up. When this happens, destructive forces have a greater chance of flourishing. For example, high-tech crime, ranging from Internet child pornography to online fraud, is on the rise in Canada, but law enforcement agencies in this country are having a hard time keeping on top of this problem. So nurses **must** be technologically competent. Technology is the cornerstone of today's health care world. Technology extends an enticing and powerful invitation to join the process of discovery, and it is easy to get caught up in the excitement of hoping that this new drug or that new procedure may prolong life just a little while longer. However, with the hope that our high tech miracles will be at least 50% successful, we can be 100% sure that the patient is not living well anymore. My husband recently commented, "If I didn't know about hospice, when I think of dying in a hospital, my impression is that I would be about to go under a steam roller, a fear of being squished out of existence before I die." Many share his perception, believing that all hospitals do is offer technology. At the other extreme, nursing homes - the other institution where death occurs most often - are seen to use no technology, to give up on technology, focusing on only making sure that fluids are running. But, if nurses are doing their work, that is not what happens. Nursing tempers the

negative effects of technology. Nursing has a role in deciding when technology is no longer doing good. Nursing doesn't stop when technology can do no more. Nurses must use technology to its fullest advantage without themselves becoming technicians.

We are faced with technology that appears to be inevitable, as powerful as nuclear energy, possibly unpoliceable, still in its infancy, and changing the way we think and the way we spend our time. Pervasive technology makes us hyper-efficient time consumers. Standing in line at an ATM the other day, I noticed that all of my line-companions and I were standing with our heads upturned watching a television screen with news on it - I guess so that we wouldn't waste the 40 seconds of standing in line. To argue against this trend would be an act of silly nostalgia. Besides, there is nothing inherently wrong in making standing in line more interesting. But what about using our time to reflect on the day, to think about our spouses, the kids, our jobs? Indeed, our effort to make ourselves hyper-efficient consumers of time through pervasive informing and entertaining may, ironically, be materially deleterious. As the sociologist Max Weber (cited in Wright, 1999) wrote about the nature of idea formulation, ideas "come when we do not expect them, and not when we are brooding and searching at our desks." Rather, they come when "smoking a cigar on the sofa or when taking a walk on a slowly ascending street" (cited in Wright). Silence nourishes thought, reflection develops wisdom, and listening begets humanity. When there's no silence, there's no room for thought.

In the middle of the 19th century, Ralph Waldo Emerson (1847) registered a lyric complaint about the oppressive force of material goods, "Web to weave and corn to grind, things are in the saddle and ride mankind." If Emerson found such modest machinery as corn grinders dehumanizing, imagine what he would think of today's technology. Today, we are more the slaves of technology - tethered to computers, cell phones, and beepers. Meanwhile, we have to cope with unprecedented change. And the more tethered we become, the faster things change, because the tethers are plugging people into the very social collaboration that drives the change. Science, technology, music, politics - flux in all these realms is hastened by the new electronic synergy. The Internet and allied technologies make us neurons in a vast social brain, a brain that keeps enticing us into making it bigger, stronger, faster. We have, you might say, a Web to weave.

What are we to make of all of this in practical, philosophical, and even spiritual terms? How to comprehend an age in which we find ourselves enmeshed in a huge information-processing system, one that seems almost to have a life of its own and to be leading us head-long into a future we can't clearly see, yet can't really avoid? In the last issue of **Time** for the 20th century, Robert Wright (1999) noted that the unfolding of technology is a process of natural evolution. Not just since Emerson's day, when the telegraph - sometimes called the Victorian Internet - made long-distance contact instantaneous, but since the very dawn of the human experience. For tens of thousands of years, technology has been drawing humanity toward the epic, culminating convergence we're now witnessing.

Technological evolution

From the very beginning, technological evolution was a social enterprise, mediated by what Wright (1999) loosely calls a social brain. In the Middle Paleolithic Age, around 50,000 BC, earliest inventions took a long time - to go from a hand axe to axes with handles took hundreds of thousands of years. There were not many neurons (also known as people) scattered across the entire planet and they were not in contact with one another. But, with each advance in subsistence technology, survival grew more secure, hastening population growth; and as the population grew, advances came more quickly. By 10,000 BC, the rate of advance had moved from one major innovation per 20,000 years to one per 200! Farming was invented in 8,000 BC, and was a kind of information-processing

technology. By radically increasing the human population that a given acre could support, families sped up the synergistic exchange of cultural information, lubricating innovation. The results were epoch making. Within 5,000 years of the inception of farming, there were dazzling technological advances, including monumental temples, big dams, and a whole new information technology - writing.

Gutenberg's printing press, up and running in Europe by the mid-15th century, was by far the most Internet-like technology in history. Eventually, it would convey detailed news of inventions, allowing people in distant lands who would never meet to collaborate on new technologies. Innovations were often in information technology - the telephone, the phonograph, colour photography. And each advance - by easing the transmission of data, whether by sound, print, or image - only raised the chances of further advances. The story of mankind is faster and vaster data processing. According to this perspective, then, the unfolding of technology is a process of natural evolution.

Perhaps, referring back to Emerson's (1847) words, it is man's destiny to weave a web that would give us the option to exercise amity or enmity over unprecedented distance. For most of us, technology is far from neutral. It shapes our choices; it directs our actions. We have a largely unexamined relationship with technology that consists to some degree of both fear and worship. "Awake" is how Buddha described his state of being. And it would serve us well to be "awake" to the consequences of technology, both good and bad. We should not shut our eyes, or close our ears, or silence a dialogue, or be seduced by technology. We must strive for a conscious awareness of technology, so we can evaluate the relevance of existing technologies with clarity and can build an appropriate relationship with technology. We must begin to nurture the power of technology instead of rejecting it or blindly embracing it. We can begin to anticipate the development of new technologies and debate the merits and the consequences in advance of the application of those technologies, and in doing so we will become less anxious about the future. In doing so, we will find a balance between technological advances and matters of the heart.

Weaving nursing's future

If, as Emerson (1847) says, we are "weaving a web," I thought searching the web for "weaving" would be a good idea, especially if I wanted to talk about weaving a tapestry for nursing's future. The experience was not what I expected. My thoughts of weaving stirred up images that were strictly high touch - an image of quilts and teddy bears with hand-woven ties, an image of the throw cover my mom gave Tom and me for an anniversary gift this year - a thick, woven, wooly fabric, soft as a lamb, and a deep verdant green. I thought about the woven bedspread that I have had since childhood. I imagined the wedding gift we received, loosely woven place mats with a little tag that said, "Hand woven in Prince Edward Island." I recalled the exhibit I visited last spring in Charlotte, NC - "Spirits of the Cloth" - which was comprised of contemporary African American wall hangings. My conception of weaving pertained to a handicraft - something created with the talented, agile, and magical fingers of a creative individual. Definitely high touch.

What did I find on the Internet? Examples of combining the traditional high touch weaving with high tech methods. Hand Jacquard weaving by Louise Lemieux Berube (2000) from Montreal. Her description of her work read as follows:

Ever since I first began exploring textiles, I have continuously worked to develop a specific approach that uses computers to combine my knowledge of textiles with my interest in abstract art and the theoretical principles of weaving structures as potential elements of creation... Via computer technology, I begin creating one of my woven images by digitalizing a photograph. The number of shades of grey in the scanned photograph is reduced, then each shade is replaced by a weaving structure. I then weave the image onto a Jacquard loom in my studio.

Another artist, Alicia Felberbaum (2000) explained her work like this:

For the past four years, the computer has replaced the loom as the essential equipment in my work. Like the loom before it, the computer has a central place in my studio. I see it as another form of weaving. As I started to work in this new medium, I realized that I was going to require a new set of skills if I were to become a digital crafts person. To be able to manipulate this new material to create a cohesive fabric, I needed to become skilled in the grammar of the computer. For me, the process was comparable to learning a new language, so that I could engage in visual conversations.

A final commentary by Barbara Layne, the artist of "Drawing Threads," added to my expanding view of weaving. Each week, digital drawings of textiles in the McCord Museum of Canadian History in Montreal will be made on a laptop computer. The drawings will be transported through the Internet to the UC Davis gallery, where they will be downloaded, printed, and mounted in the gallery. The project envisions how the museum will function in an electronic age.

Can we envision how nursing will function in the electronic age? I believe we can if we build that technological future around the central core of high touch. In the 1980s, Fritjov Capra (1982) identified his vision of nursing as a social force. He foresaw a new system of primary patient care:

being forcefully advocated today by nurses who find themselves at the forefront of the holistic health movement... These highly educated and motivated nurses will be best qualified to take on the responsibilities of health education, counseling and preventive health care (p.414).

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Gretta Styles (1989), a past dean of UCSF School of Nursing and a past president of ICN, affirms:

Our view of the social significance of nursing is based in large part on a clear conception of nursing - of its social value; of its past, present, and future accomplishments. In a word this means vision, a quality that is a source of inner direction and outward inspiration (p.124).

Ten years ago, my colleague, Kathy Oberle and I published an article that still remains one of my favourite publications (Davies & Oberle, 1990). We described a model of supportive care nursing. The work derived from my discussions with Alice Weinlick who then was in a clinical specialist role at the Cross Cancer Institute in Edmonton. One day, Alice expressed frustration with the weekly reports she had to complete. She noted that on the days when she felt as if she had done little of significance, she had lots of numbers to record - numbers of phone calls, consults, referrals. On the days when she felt she really made a difference in someone's life, she had few numbers to fill in. We decided to see if we could find an explanation. What resulted was a conceptualization of nursing, applicable not just to Alice, but, we have since learned, applicable to many nurses in many settings.

Nursing occurs in the context of valuing. Nurses connect with patients and family members, empower them to do what they can do for themselves, help them to find meaning in their situation, and "do for" patients when they cannot "do for" themselves. At the core of the model is preserving integrity of both the patient and the nurse. The personal and the professional selves are not isolated one from the other. As you can see, "doing for" is only one part of nursing care - it's the part that has to do with procedures, techniques, skills, and equipment. It's the part that focuses on procedures, method, and evidence-based practice. But it's important to remember that a nurse can "do for" patients without really connecting, empowering, or helping the patient find meaning. I am sure you have all started an IV, changed a colostomy bag, or administered medications without always connecting with the person who was on the other end of the procedure. In such situations, you may have given adequate and safe care, but you did not give optimal care. Unfortunately, this is the kind of care that is occurring more often in our health care system, due to too few nurses to do too many tasks. And, what happens when the "doing for" part of nursing takes front and centre stage? It's not a problem, I suppose, for nurses who believe that this is what nursing is all about. But, for those of us who believe that nursing is based in human interaction, in relationship, it's a major problem. We experience cognitive dissonance between what we believe nursing should be, and what it has become. How do we respond? We either leave nursing because we cannot reconcile the dissonance, or we stay and adopt the cultural mantra. We convince ourselves that what we are doing is really the best we can do; we are giving safe and adequate care, and that's all that matters. We become part of the system that we once criticized and vowed to improve for the benefit of the patients we cared for and about as

people, as persons. But there is another, more effective response. It's the one voiced by Hathaway (1943) when she said:


Then and there I invented this rule for myself to be applied to every decision I might have to make in the future. I would sort out all the arguments and see which belonged to fear and which to creativeness, and other things being equal, I would make the decision which had the larger number of creative reasons on its side. I think it must be a rule something like this that makes jonquils and crocuses come pushing through the cold mud.

And, that makes roses bloom after winter.

As we look for evidence for nursing practice, let us look not only at evidence for procedural interventions. Let us also focus on that part of nursing that is not easily measurable - in the same way that the beauty of a rose is not measurable, but rather symbolizes the immeasurable contributions of a gentle touch, a reassuring word, a consistent relationship over time, a genuine concern for the well-being of one's patients and colleagues, a belief that quality of life is sometimes more important than quantity. Let us call for an evidence base that shows that artful human contact has positive effects and supports health. Technology doesn't help people be human beings in different contexts, but if nursing helps the human element, then let us have more evidence of that. If we need evidence to make our case, then let's get the evidence. A First Nations elder, known for his ability to fish, was asked how it was that he could always catch so many more fish than anyone else. He answered simply, "I think like a fish." We must learn to think like a fish - think not as a nurse, but as the recipient of nursing care. Imagine not what you can do for patients, but what you would want from a nurse if you were the patient, if you were the family. Imagining what you would want from nurses - that's one way to broaden our vision.

Let us envision nursing as a voyage of discovery that lies not in seeing new vistas, but in seeing with the heart. Let us treasure moments of connection and inspiration. Let us remember that to find meaning is to see things differently. As gatherers and users of evidence, we are trained to be objective. But one cannot find meaning at a distance. Let us not depend only on rulers as our only way of knowing. Let us also incorporate the rose. In the familiar song by Seals and Croft:

*Forever like the rose
I suppose that's the way to live
Strong and ever giving
Always living with a purpose and a goal
To blossom day to day...
Forever like the rose.*

Let our vision of nursing incorporate service, not as a technique, but as a relationship between two human beings who bring their combined strength to the table. Let us not see ourselves as experts dealing with problems, but as weavers of relationships. Tapestries woven in service of our fellow human beings will reach out and beyond what we expect or know. Let that be the tapestry we weave. 

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Tisser les soins de demain, à l'aide de règles et de roses

par Betty Davies

Lorsqu'on m'a invitée à présenter ce discours d'ouverture, on m'a demandé de mettre en valeur le thème de la conférence - Tisser la nouvelle tapisserie des soins infirmiers en oncologie - ainsi que les concepts particuliers d'unité, de créativité et de vision. J'ai récemment lu un grand nombre d'écrits affirmant que la vision constitue une condition préalable nécessaire à la réussite. C'est également une condition sine qua non de l'unité et de la créativité. Tout cela fait que je vais me concentrer sur le concept de vision.

Quelle est donc la vision qui guide nos pas à mesure que nous tissons la tapisserie des soins infirmiers en oncologie à l'aube du nouveau millénaire? Qu'entend-on par le mot vision? Il s'agit essentiellement d'un parcours mental qui nous mène du connu à l'inconnu et nous permet de construire l'avenir à partir d'un assemblage de faits, d'espairs, de rêves, de menaces et d'opportunités. La vision est l'image de la situation future possible et souhaitée. Cette image ou vision peut être aussi vague qu'un rêve ou aussi précise qu'un énoncé de but ou de mission. Une vision fait toujours référence à un état futur, à une situation qui n'existe pas encore et qui n'a jamais existé auparavant. Tout comme les trajectoires de personnalités du Canada présentées dans un récent numéro de la revue *Maclean's* ont inspiré le monde entier, de telles trajectoires peuvent régir la réussite d'une profession. Ces personnalités, dont Terry Fox, ont su adapter leur vision initiale aux conditions changeantes, et les infirmières en oncologie doivent faire de même pour ne pas se laisser dépasser par l'évolution rapide du monde.

Nous nourrissons toutes des rêves à propos du futur. La majorité d'entre nous s'imaginent plus prospères, plus riches et plus heureuses qu'à l'heure actuelle, mais on n'atteint pas ces buts en rêvant. Au contraire du rêve, la vision nous aide à nous préparer, nous-mêmes et notre profession, à créer des opportunités pour l'avenir et à les faire fructifier. La vision est une compétence à la fois offensive et défensive; d'une part, elle nous permet de tracer la voie du changement et d'autre part, de réagir aux changements externes. La vision est une caractéristique des individus et des groupes d'individus.

Les chefs visionnaires possèdent un trait commun - ils ont tous une vision irrésistible de leur travail et partagent leur rêve. Leur compréhension profonde de leur organisme, de leur

profession et de son environnement garantit la clarté de la vision. Celle-ci exige l'habileté d'artisans, pas celle de techniciens. Les artisans savent exactement ce qu'il faut faire pour l'atteindre. Ensuite, ils font appel à leurs outils et leurs matériaux pour façonner le produit, l'adapter et le rajuster à mesure qu'il progresse, en gardant constamment à l'esprit l'apparence et la texture du but recherché. En revanche, s'ils se limitaient à un rôle de techniciens en suivant tout simplement une série d'instructions dénuée de toute vision, le produit obtenu ne serait pas de qualité supérieure.

Une nuit, je circulais sur une route illuminée par la lune qui semblait de taille démesurée. Je n'ai pas pu m'empêcher de m'arrêter pour l'admirer et de m'interroger sur la distance qui me séparait de ce merveilleux symbole de l'espace. Je trouvais prodigieux que l'on ait réussi à "conquérir" l'espace, à avoir établi une voie entre notre planète et son satellite et à faire marcher un être humain sur la Lune. Je me suis demandée quelle vision avait pu guider les expéditions en direction de notre satellite. Cette nuit-là, tandis que je rentrais chez moi, et à des nombreuses reprises depuis, j'ai souvent réfléchi aux thèmes de l'espace, de la vision et de la création de tapisseries pour le futur et je les ai examinés à diverses reprises, de diverses manières et pour différentes raisons.

Le terme espace s'utilise de biens des façons et j'imagine que chacune de ses formes possède un incroyable potentiel. Il y a les espaces qui se créent entre les gens et les espaces qui existent entre les bâtiments. Il y a aussi l'espace auquel nous donnons le nom de temps et celui que nous appelons distance. Je pense aussi à l'espace en chacun de nous que nous qualifions d'intérieur. Mais je crois que l'espace le plus commun est celui qui attend de nous qu'on le découvre. C'est celui qui nous mène vers l'étonnement, la déception ou, tout simplement, vers la fin de notre périple ici-bas. Il y a ceux d'entre nous qui s'efforcent continuellement de franchir les espaces qui s'offrent à eux, un phénomène étrange mais vrai. Je sais qu'il y a des gens qui doivent absolument se retrouver sur la mer dont l'horizon sans fin les attire, s'ils n'en sont pas trop loin. Il leur est impossible de rester bien longtemps sur le rivage sans se mettre en quête d'une embarcation pour se retrouver au beau milieu de cet espace. Il y en a d'autres qui escaladent les montagnes, en partie parce qu'elles représentent un espace qu'ils désirent franchir. Je suppose aussi, que ce qui motive les explorateurs à aller toujours plus loin, dans leur for intérieur, est le besoin de remplir les "blancs" de l'espace. Mais vous êtes-vous demandé un jour d'où vient cet appel et cette envie irrésistibles de remplir ces espaces? Ne vous êtes-vous jamais demandé pourquoi nous quittons des situations confortables pour nous aventurer dans des territoires où règnent l'incertitude et le manque de sécurité? Qu'est-ce qui amène les explorateurs à fouler des territoires étranges, nouveaux et parfois hostiles? Qu'est-ce qui leur a fait quitter le littoral des grands océans pour aller toujours plus loin au-delà de l'horizon? Un rêve? Une vision?

Comment élabore-t-on ce genre de vision? Il n'est pas toujours aisé de créer des visions percutantes. Souvent, les visions se heurtent au ridicule et aux moqueries, tandis que d'autres fois, on les ignore totalement. Cela ne veut pas dire qu'on ne devrait pas créer de vision pour autant. Mais il faut savoir que cet exercice exige de formidables efforts. La plupart des gens essaient d'élaborer une vision à partir des circonstances dans lesquelles ils se trouvent alors que pour créer une vision authentique, il faut qu'elle soit conçue indépendamment des circonstances. Il importe également de ne pas tenir compte de la

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possibilité ou de l'impossibilité apparentes de sa réalisation. Puisque la formation de la majorité des gens les amène à penser en termes de réaction appropriée face aux circonstances, la malencontreuse habitude de limiter ce que l'on veut à ce qui semble réaliste et possible nuit à la créativité. Une vision ne demande pas: "Que voulez-vous obtenir à la lumière des options disponibles?" Elle demande plutôt: "Qu'est-ce que vous voulez?" En fait, on découvrira avec étonnement que bon nombre d'entre nous sont presque incapables de décrire tout simplement ce qu'ils veulent créer. Et pourtant, en matière de création, la toute première intervention consiste justement à concevoir ce que l'on veut créer.

Une vision authentique est l'image conceptuelle d'un résultat qu'un créateur ou une créatrice veut concrétiser. Si cette vision ne naît pas d'une évaluation des besoins, d'une définition des problèmes dominants ou d'une analyse des tendances relatives aux soins de santé, où trouve-t-elle son origine? Il y a des gens qui abordent la vision comme s'il s'agissait d'un trésor bien dissimulé qu'il convient de découvrir et de révéler. Malgré cela, la conception de ce que l'on se propose de créer n'est pas, elle non plus, un processus de révélation. Certains privilégient les remue-ménages dont le but est de contourner les idées reçues en faisant appel à l'imagination générée par les associations libres. Mais ces dernières ignorent régulièrement le fond du problème, soit la réponse à la question on-ne-peut-plus-simple, "Qu'est-ce que je veux créer?". "Que seront les soins infirmiers de demain, selon moi?" Parvenir à concevoir ce que l'on veut est un processus à la fois d'une simplicité apparente et d'un raffinement profond. La création d'une vision exige des efforts, à la fois conscients et inconscients, mais quand il s'agit de lui donner forme, le créateur, la créatrice le fait au fil de ses pensées, de ses observations, de ses méditations et de ses questionnements. Par exemple, le vent qui gonflait un drap séchant sur une corde à linge est à l'origine de la création d'un ballon de grande taille, l'ancêtre du Zeppelin. Une toile d'araignée tendue en travers d'une allée de jardin a inspiré la création du pont suspendu. Dans leur imagination, les créateurs et les créatrices voient ce qui n'est pas là. Ensuite, ils commencent à concrétiser ce qui n'existait pas encore.

On ne nous a pas encouragées à créer des visions de résultats souhaités. On a appris à la plupart des gens à concentrer leur attention sur la méthode: respecter les procédures, remplir des formulaires, adhérer aux lignes directrices. Ces activités permettent de répondre à la question "Comment puis-je concrétiser l'objet de mes souhaits?" C'est une question qui a son utilité une fois que l'on sait ce que l'on veut obtenir, mais qui n'est d'aucune aide auparavant. Et la plupart des systèmes d'éducation demandent aux apprenants de se tourner, avant tout, vers la méthode. Prenons par exemple le concept de la pratique fondée sur des données probantes, un thème courant dans les revues professionnelles de toutes les disciplines de la santé. On décrit généralement la pratique fondée sur des données probantes comme étant les soins prodigués aux patients atteints d'une maladie ou d'une condition particulière et ayant comme base les meilleures pratiques établies en fonction de données scientifiques. En théorie, une utilisation plus fréquente de lignes directrices fondées sur les résultats, notamment celles qui favorisent la détection et la surveillance des patients à risque élevé, ne diminuerait pas seulement les erreurs qui se produisent dans le système, mais elle se traduirait par de meilleurs résultats au sein de la population en intervenant plus précocement auprès d'un nombre accru de patients. Bien que l'on considère habituellement que la pratique fondée sur des données probantes en est encore à ses débuts, on ne manque pas de protocoles, de voies critiques et de meilleures pratiques cliniques pour tous les aspects des soins, des pontages coronaires extrêmement onéreux à la surveillance quotidienne à

domicile des patients atteints d'asthme et de diabète. Le but est de combler le fossé entre les connaissances et les pratiques. Un but qui n'est d'ailleurs pas sans mérite.

À titre d'infirmières, nous avons l'obligation de prodiguer les meilleurs soins possibles. Nous assumons une responsabilité sociale et professionnelle de dispenser des soins infirmiers qui reposent sur d'excellents principes et dont on sait qu'ils font la différence pour les patients. Plutôt que de découvrir ce qui donne de bons résultats par tâtonnements ou de manière aléatoire, nous nous devons d'administrer des soins fondés sur des données confirmant que nos interventions sont sécuritaires et qu'elles améliorent le degré de confort des patients.

Malgré tout, je demeure quelque peu sceptique. Cela vient peut-être du fait que j'exerce la profession infirmière depuis 30 ans – assez longtemps pour avoir vécu les prodiges que nous promettaient le processus infirmier, les diagnostics infirmiers, les théories infirmières et la recherche infirmière elle-même. Ne devaient-ils pas donner à la pratique des soins infirmiers la base scientifique qui bénéficierait aux patients et le professionnalisme qui bénéficierait à notre discipline? Je ne veux pas dire par là que ces aspects étaient mal guidés, manqués ou nuisibles; ils font partie de l'histoire du développement des soins infirmiers et ils ont joué et continuent de jouer un rôle utile. Chacun de ces concepts a enflammé notre imagination collective et nous a propulsées vers une nouvelle phase de croissance et de développement.

Le processus infirmier, par exemple, préconise, pour les soins infirmiers, une approche privilégiant la résolution de problèmes. Vous en connaissez toutes les quatre étapes - analyse, planification, intervention et évaluation. Lorsque j'observais les étudiantes qui respectaient méthodiquement et systématiquement les lignes directrices d'évaluation des patients, j'étais impressionnée par les descriptions détaillées qu'elles faisaient des situations. Mais parfois, c'est à la lettre qu'elles suivaient ces lignes directrices et elles ne montraient ni la capacité ni le désir de les mettre un tant soit peu de côté pour vraiment voir et entendre la personne qui faisait l'objet de leur analyse. L'accent mis sur la collecte de l'information les empêchait de réaliser que l'analyse elle-même constitue une intervention. *La façon dont* une infirmière recueille les données d'évaluation du patient a une répercussion sur les données rassemblées. En outre, les autres enseignantes et moi soulignons le fait que le processus infirmier n'est pas un processus séquentiel et pourtant, c'est d'une manière tout à fait linéaire que nous enseignons les quatre étapes du processus. Nous ne mettons pas en pratique ce que nous prêchions. Et nous savons toutes que les enfants et les étudiants se ressemblent en ce qu'ils apprennent beaucoup plus de ce que leurs parents et enseignants *font* plutôt que de ce que ces symboles d'autorité *disent*. Le processus infirmier ne constituait pas un problème en lui-même. Le problème venait plutôt de la conceptualisation de processus complexes sous une forme linéaire qui nous amenait à privilégier les procédures et la méthode.

Et ceci est à l'origine de mes préoccupations au sujet de la pratique fondée sur des données probantes. Elle nous pousse, elle aussi, à privilégier les procédures et les méthodes qui fournissent des données quantitatives de la différence que certaines interventions ou certains traitements peuvent faire dans la vie des patients et de leur famille, à privilégier les données de "rigueur scientifique". Les données scientifiques sous-entendent normalement une approche quantitative visant à isoler les causes et effets, à opérationnaliser des relations théoriques et à mesurer et à quantifier les phénomènes (Flick 1998). Traditionnellement, la preuve scientifique essaie de donner un sens aux chiffres – c'est le règne de la règle. Elle s'appuie habituellement sur l'opinion

traditionnelle de “*ce qui compte*”. Les deux acceptations du terme *compter* nous viennent du verbe latin *computare*. *Com* signifie *ensemble*, et *putare* veut dire *penser*. Compter veut donc dire *se rassembler pour penser*. *Ce qui compte* se rapporte à la relation que deux êtres humains établissent pour découvrir des significations communes et non pas pour faire de l’arithmétique. *Ce qui compte*, c’est de réaliser que nous touchons les autres tout comme ils nous touchent. *Ce qui compte* pour une mourante, c’est de laisser à son petit-fils un gage d’amour en terminant le jeté de lit qu’elle tisse pour lui.

Il nous faut trouver de nouvelles approches pour la collecte des données *qui comptent*, étant donné qu’une grande partie des obstacles à la dispensation de soins de qualité ne sont pas d’ordre clinique au sens traditionnel du mot. Beaucoup sont structurels – p. ex. le fait de ne pas avoir suffisamment d’infirmières pour dispenser les soins infirmiers de base. La résolution de ces problèmes exigera des efforts qui dépassent largement l’élaboration de protocoles fondés sur des données probantes, la mise au point d’instruments permettant de mesurer les différences au niveau des résultats.

Rassemblées comme nous le sommes au bord des eaux agitées et polluées des systèmes de soins de santé, qu’est-ce qui nous pousse à vouloir nous aventurer dans cet espace inconnu? Qu’est-ce qui nous permet d’espérer et de croire que la situation va s’améliorer? Notre vision, pardi! Notre vision de ce que les soins infirmiers peuvent devenir. C’est bien ça qui nous pousse à continuer – même si parfois la vision ne nous illumine pas plus que la faible lueur d’une chandelle. Cependant, durant les hivers de l’Alberta, mon père gardait toujours une chandelle dans la voiture parce que la chaleur qu’elle produit à elle seule peut empêcher une personne de mourir de froid. N’oublions pas que ce n’est pas dans la lumière mais bien dans la chaleur que nous trouvons le soutien dont nous avons besoin.

Dans le monde contemporain, la chaleur que procurent les soins infirmiers risque de disparaître face à l’omniprésence des technologies. Les technologies ont de puissantes répercussions qui ne sont pas neutres, mais sont à la fois positives et négatives. J’ai eu le privilège d’être à la présidence de la Fondation des infirmières et infirmiers du Canada (FIIC) lors de son 25^e anniversaire. À cette occasion, nous avons mené une campagne de levée de fonds afin d’assurer la viabilité de cet organisme. Nous avons choisi le slogan “Toucher réconfortant, technologie de pointe” qui résumait bien ce que nous pensions de la situation: à mesure que le système de santé embrassait la technologie de pointe, les soins infirmiers devaient continuer de promouvoir non seulement les facettes technologiques des soins mais aussi l’importance du toucher.

Qu’est-ce qu’on entend par technologie de pointe? Menus, souris, sites Web, réseaux, Internet. Sauvegarde de fichiers, virus, fusion de données, purge, surtension, liens, câblage. Panne d’ordinateur, raccourci, surcharge, numérique, formatage. Elle prend la forme de machines, de matériel, d’écrans d’ordinateur, d’écrans de contrôle et de télévision. Elle est également synonyme de transfusion sanguine, d’amputation, de greffe de moelle osseuse et de prothèses. La technologie de pointe, c’est aussi le projet Génome humain. Elle va de pair avec l’innovation, le progrès, la lutte contre les maladies, les découvertes futures.

Et qu’est-ce que le toucher réconfortant? C’est l’amour que l’on porte à un enfant, c’est prendre le bras de sa mère lorsqu’elle enjambe le caniveau parce qu’on remarque que ses pas ne sont plus aussi assurés qu’avant, c’est la voix de son compagnon de vie au téléphone, c’est l’odeur de pain frais dans la cuisine, c’est le ciel rose et violet du coucher de soleil, c’est le ravissement face aux montagnes, c’est les rires échangés entre les grand-parents et leurs petits-enfants. C’est la larme qui coule de l’œil de votre patiente qui vient d’apprendre que sa biopsie est négative, c’est la

main que vous posez sur l’épaule de la patiente suivante qui, elle, n’a pas cette chance. C’est la voix douce de la fille qui calme son père agité, c’est la période de calme au milieu de la nuit lorsque tout le monde dort, c’est le fait de pouvoir faire démarrer, dès le premier essai, la perfusion d’ordinaire récalcitrante. C’est quand une femme vous fait part de ses craintes au sujet de l’avenir, c’est l’entendre adresser un “Je t’aime” à son époux mourant. C’est les draps propres que vous glissez sous ce patient en sueur dont la température atteint 40 °C et la douce brise qui entre par la fenêtre ouverte. C’est le regard que vous donne votre collègue lorsque vous lui annoncez que vous vous occuperez de ses patients pendant qu’elle va prendre un café juste après le décès de l’un d’eux. C’est le sentiment d’avoir bien accompli son travail à la fin de la journée.

J’ai consacré une partie essentielle de ma carrière aux soins palliatifs pour les enfants et leurs proches. Il m’a toujours semblé que les éléments fondamentaux des soins palliatifs – sensibilité dans toutes les dimensions de la vie à la personne globale, à la famille, ainsi qu’aux individus que nous qualifions du nom de patients – concrétise mieux ma vision des soins infirmiers que toute autre expérience professionnelle vécue jusqu’à présent. Les soins palliatifs me plaisent parce qu’ils me donnent l’occasion d’être le type d’infirmière que j’ai toujours rêvé d’être. Je considère aussi depuis toujours que je suis une infirmière en oncologie. Comme nous jetons les bases de la vision des soins infirmiers en oncologie de demain, j’aimerais que ces soins suivent le modèle des soins palliatifs plutôt que de choisir la seule voie de la technologie.

Il ne fait aucun doute que la technologie de pointe a amélioré la vie de nos patients, engendré de meilleurs résultats pour eux et économisé beaucoup de temps au personnel infirmier. Pensez un peu aux simples thermomètres à mercure et au temps qu’on passait à les nettoyer, à les stériliser, à les agiter et à bien repérer la petite colonne grise. Il nous arrive de nous souvenir, avec nostalgie, des moments calmes que nous passions aux côtés des patients en attendant que le mercure grimpe dans sa colonne de verre. Mais cela se passait-il vraiment ainsi? Oui, parfois. Mais je me souviens que la plupart du temps, je faisais une visite pour placer un thermomètre dans la bouche de chaque patient et que je repassais un peu plus tard pour en faire le relevé. Au lieu d’envisager ce que les soins infirmiers devraient être et pourraient être, nous n’aspérons qu’à retrouver ce qu’ils étaient, à la lumière diffuse de nos souvenirs.

Les technologies de jadis nous servent de points de référence. Elles caractérisent certaines époques de notre vie à toutes et déclenchent des souvenirs... et les émotions qui les accompagnent. La technologie de pointe n’a pas encore de point de référence. Elle engendre l’espoir d’une vie meilleure mais elle n’éveille aucun souvenir. Est-ce alors que la technologie de pointe se transforme en technologie désuète ou fait plus remarquable encore, est-ce alors qu’elle devient toucher réconfortant?

La technologie de pointe se transforme en toucher réconfortant à force de longévité et de familiarité culturelle. De nos jours, une navette de métier à tisser remplie de fil appartient à la catégorie toucher réconfortant. Mais il y a quatre mille ans, elle représentait les tout derniers progrès technologiques en Assyrie et en Égypte. Et aujourd’hui, c’est un objet de musée appartenant à la catégorie toucher réconfortant. Veillons à ce que les soins infirmiers eux-mêmes ne soient pas relégués à la section toucher réconfortant du musée des professions de la santé.

C’est le sort qui nous attend peut-être si nous ne prenons pas le virage technologique – comme cela s’est produit pour ceux et celles qui ont été dépassés par le progrès. Et quand cela arrive, les forces de la destruction ont de plus grandes chances de

s'épanouir. Par exemple, la criminalité technologique, qui va de la pornographie juvénile sur Internet aux fraudes en ligne, est en augmentation au Canada, mais les autorités policières de notre pays ont bien du mal à rester dans la course. Il faut donc que les infirmières possèdent les compétences technologiques requises. La technologie est la pierre angulaire du monde contemporain des soins de santé. Elle lance une invitation irrésistible et percutante de se joindre au processus de découverte, et il est facile de se mettre à espérer que tel nouveau médicament ou tel nouvel acte pourrait prolonger la vie un tout petit peu plus. Certes, on peut se prendre à espérer que les miracles de la technologie de pointe se solderont par au moins 50 % de réussite, mais on peut être certaines, à 100 %, que le patient, lui, a perdu sa qualité de vie. Mon mari m'a récemment fait le commentaire suivant: "Si je ne savais pas ce qui se passe dans les hospices, lorsque je pense qu'un jour il me faudra aller à l'hôpital quand je serai au seuil de la mort, j'ai l'impression qu'on m'y ferait passer sous un rouleau compresseur, qu'on ferait sortir de moi toute trace de vie juste avant que je n'expire." Il n'est pas le seul à avoir cette perception, et beaucoup de gens croient que les centres hospitaliers n'ont que la technologie à offrir. À l'autre extrême, on constate que dans les foyers pour personnes âgées – l'autre type d'établissement où les gens meurent le plus souvent – la technologie brille par son absence, qu'on y a renoncé et qu'on accorde la priorité aux seules fonctions d'évacuation. Mais, si les infirmières font leur travail comme il faut, ce n'est pas ce qui se passe. Les soins infirmiers tempèrent les effets négatifs de la technologie. Ils jouent un rôle quand il faut décider si la technologie a perdu son utilité. Les soins infirmiers ne s'arrêtent pas lorsque la technologie n'est plus d'aucun ressort. Il importe que les infirmières tirent le maximum de la technologie sans pour autant devenir de simples techniciennes.

Nous devons composer avec des technologies qui nous semblent incontournables, d'une immense puissance telle que l'énergie nucléaire, d'une réglementation potentiellement difficile, qui en sont encore à leurs débuts, mais qui changent notre façon de penser et d'occuper notre temps. La technologie omniprésente nous transforme en consommateurs de temps super efficaces. L'autre jour, je faisais la queue devant le guichet automatique bancaire et je me suis aperçue que nous étions tous en train de regarder un téléviseur qui diffusait les nouvelles – je suppose que ce serait une perte de temps que de passer 40 secondes à ne faire que la queue. Et que de s'opposer à cette tendance serait un acte de nostalgie ringarde. De toute manière, je ne trouve rien à redire, sur le fond, au fait qu'on veuille nous distraire quand nous faisons la queue. Mais nous pourrions tout autant profiter de ces quelques secondes de répit pour passer en revue les activités de la journée, penser à notre conjoint, à nos enfants, à notre emploi. En fait, les efforts que nous produisons pour devenir des consommateurs super efficaces de temps en accordant une place toujours plus grande à l'information et au divertissement, pourraient, et c'est ironique, nous nuire sur le plan matériel. Comme le sociologue Max Weber (cité dans Wright, 1999) l'a si bien dit sur la nature de la formulation d'idées, celles-ci "nous viennent quand nous ne nous y attendons pas, et pas quand nous ruminons des pensées et nous nous perdons en réflexions à notre bureau." Elles nous viennent plutôt quand "nous sommes en train de fumer un cigare sur le sofa ou que nous nous promenons dans une rue qui monte légèrement" (passage cité dans Wright). Les pensées se nourrissent du silence, la sagesse se développe à force de réflexion et l'écoute éveille l'humanité. Sans silence, la pensée n'est pas.

Au milieu du 19^e siècle, Ralph Waldo Emerson (1847) a composé une ritournelle à propos de la force oppressive des biens

matériels: "Des toiles à tisser et du maïs à mouder, la selle est préparée et l'humanité prête pour la chevauchée" [traduction libre]. Si Emerson jugeait déshumanisantes des machines aussi peu perfectionnées que des broyeurs de maïs, imaginez un peu ce qu'il penserait de la technologie moderne. Aujourd'hui, nous en sommes les esclaves, attachés que nous sommes à nos ordinateurs, téléphones cellulaires et autres téléavertisseurs. En même temps, il faut que nous nous adaptions à des changements sans précédent. Et plus nous sommes reliés aux machines, plus les choses changent vite, parce que les connexions permettent aux gens de participer à la collaboration sociale sous-tendant ces changements. La science, la technologie, la musique, la politique – dans tous ces domaines, le flux est amplifié par la nouvelle synergie électronique. Internet et les technologies connexes font de nous les neurones d'un gigantesque cerveau social, un cerveau qui nous encourage à en développer la taille, la puissance et la vitesse. On pourrait dire qu'il nous faut tisser l'hypertoile qu'est Internet.

Qu'allons-nous faire de tout cela en termes pratiques, philosophiques et même spirituels? Comment saisir une époque où nous nous retrouvons aux prises avec un gigantesque système de traitement de l'information qui semble mener une vie totalement autonome et qui nous précipite vers un avenir que nous entrevoyons à peine mais que nous ne pouvons éviter? Dans le dernier numéro de Time publié au 20^e siècle, Robert Wright (1999) déclarait que l'essor de la technologie s'apparentait à un processus d'évolution naturelle. Et pas seulement depuis l'époque d'Emerson lorsque le télégraphe – auquel on donne parfois le nom d'Internet victorien – a permis de communiquer instantanément sur de longues distances, mais bien depuis les tout premiers temps de l'expérience humaine. Depuis des milliers d'années, la technologie pousse l'humanité vers la convergence épique et déterminante dont nous sommes les témoins actuellement.

Depuis le tout début, l'évolution technologique était une initiative sociale, dont la médiation était laissée à ce que Wright (1999) appelle en termes généraux un cerveau social. Au Paléolithique moyen, vers 50 000 avant J.-C., les premières inventions s'échelonnaient sur de longues périodes – ainsi, il a fallu attendre des centaines de milliers d'années pour passer des bifaces aux haches munies d'un manche. Il n'y avait pas beaucoup de neurones (aussi connus sous le nom d'êtres humains) sur notre planète et ils étaient si dispersés qu'ils n'étaient pas en contact les uns avec les autres. Mais, chaque progrès de la technologie de subsistance augmentait les chances de survie et favorisait la croissance de la population qui accélérât, à son tour, la cadence des progrès. Dès 10 000 avant J.-C., le taux de progrès était passé d'une grande innovation tous les 20 000 ans à une tous les 200 ans! L'agriculture, inventée en 8 000 avant J.-C., était une sorte de technologie de traitement de l'information. En augmentant radicalement le nombre de personnes qu'un arpent de terre pouvait nourrir, les familles ont précipité les échanges synergiques d'information culturelle, graissant par là même les rouages de l'innovation. Les résultats furent historiques. Moins de 5 000 ans après l'introduction de l'agriculture, d'étonnants progrès technologiques voyaient le jour, notamment la construction de temples monumentaux et de grands barrages ainsi que l'écriture, une toute nouvelle technologie de l'information.

La presse à imprimer de Gutenberg, utilisée en Europe dès le milieu du 15^e siècle, est la technologie qui, de toute notre histoire, ressemble le plus à Internet. Elle a servi à diffuser des rapports détaillés des inventions, permettant ainsi à des gens de contrées éloignées, qui n'auraient jamais eu la possibilité de se rencontrer, de collaborer à la création de nouvelles technologies. D'ailleurs, les innovations concernaient souvent la technologie de l'information – le

téléphone, le phonographe, la photographie en couleur. Et chacun de ces progrès – qui facilitaient la transmission de données sonores, imprimées ou illustrées – ne faisait qu'améliorer les chances d'apparition de nouveaux progrès. L'histoire de l'humanité relève d'un traitement de données plus rapide et plus vaste. Vu sous cet angle, l'épanouissement de la technologie est un processus d'évolution naturelle.

Pour en revenir à la citation d'Emerson (1847), le destin de l'homme est de tisser une toile qui nous permet de faire connaître la concorde ou l'hostilité sur des distances jamais atteintes auparavant. Pour la majorité d'entre nous, la technologie n'a rien de neutre. Elle façonne nos choix, elle oriente nos actions. Nous entretenons avec la technologie des liens qui échappent encore à l'analyse, caractérisés, dans une certaine mesure, par la peur et la vénération. Bouddha retenait le mot éveil pour décrire son état de conscience. Et nous ferions bien de nous éveiller aux répercussions de la technologie, qu'elles soient bonnes ou mauvaises. Il ne faut pas que nous nous fermions les yeux ou nous bouchions les oreilles, ou que nous étouffions le dialogue, ou que nous nous laissions séduire par la technologie. Nous devons nous efforcer de nous y sensibiliser de manière consciente afin de pouvoir évaluer clairement la pertinence des technologies existantes et bâtir une relation appropriée avec elles. Il nous faut cultiver le pouvoir de la technologie plutôt que de la rejeter ou de l'accepter aveuglément. Nous pouvons anticiper la mise au point de nouvelles technologies et discuter de leurs mérites et de leurs répercussions avant qu'elles ne commencent à être appliquées et ce faisant, nous nous inquiéterons moins de ce que l'avenir nous réserve. Cela nous aidera à trouver l'équilibre entre les progrès technologiques et les émotions humaines.

Si, comme Emerson (1847) l'a écrit, nous "tissons une toile", j'ai pensé que je ferais bien de rechercher le terme "tisser" dans l'hypertoile, surtout si je voulais parler du tissage de la tapisserie des soins infirmiers de demain. L'expérience n'a pas donné les résultats escomptés. J'avais en tête des images liées uniquement au toucher réconfortant - des images de courtepoinées et d'oursours portant une cravate tissée à la main, du jeté que ma mère nous a offert à Tom et à moi pour célébrer notre anniversaire de mariage cette année – un tissu vert foncé épais en laine tissée, doux comme la peau d'un agneau. J'ai pensé au couvre-lit tissé que je possède depuis mon enfance. Je me suis souvenue d'un des cadeaux de mariage que nous avons reçus, des napperons à la texture lâche dont l'étiquette disait "Tissé à la main dans l'Île-du-Prince-Édouard. Je me suis rappelée l'exposition "Spirits of the Cloth" que j'avais visitée à Charlotte, Caroline du Nord, qui présentait des pièces murales contemporaines d'artistes textiles afro-américaines. Ma conception du tissage était synonyme d'artisanat – un objet créé par les doigts talentueux, agiles et magiques d'une personne créatrice. Rien que du toucher réconfortant.

Et qu'ai-je trouvé sur Internet? Des exemples de combinaison du tissage traditionnel – toucher réconfortant – et de méthodes relatives aux technologies de pointe. Du tissage jacquard réalisé à la main par Louise Lemieux Bérubé (2000) de Montréal. Elle décrit son œuvre de la manière suivante:

Depuis le début de ma recherche en textile, j'ai développé une approche particulière qui, à l'aide des outils informatiques, allie mes connaissances des textiles, mon intérêt pour le platicisme abstrait et les principes théoriques des structures du tissage comme éléments potentiels de création... La création de mes images tissées débute par la digitalisation d'une photo. Le nombre de valeurs de gris ou de couleurs est réduit, puis chaque valeur est remplacée par une armure de tissage. L'image est tissée à la main sur mon métier Jacquard dans mon atelier.

Une autre artiste, Alicia Felberbaum (2000) explique ainsi son

approche:

Voici déjà quatre ans que l'ordinateur a remplacé mon métier à tisser en tant qu'instrument essentiel dans mes travaux. Tout comme le métier avant, l'ordinateur occupe une place centrale dans mon studio. J'y vois une autre forme de tissage. Quand j'ai commencé à travailler avec ce nouveau médium, j'ai compris qu'il me faudrait acquérir un nouvel ensemble de compétences si je voulais devenir une artisane du domaine de la numérisation. Pour être à même de manipuler ce nouveau matériau en vue de créer un tissu cohérent, il fallait que je maîtrise la grammaire informatique. Pour moi, ce processus s'apparentait à l'apprentissage d'une langue étrangère, tout cela, afin que je puisse engager des conversations visuelles.

Un dernier commentaire, de Barbara Layne, l'artiste ayant créé "Drawing Threads," a élargi plus encore mon entendement du tissage. Chaque semaine, des illustrations de textiles du Musée McCord d'histoire canadienne à Montréal seront produites à l'aide d'un ordinateur portatif. Ces illustrations seront expédiées, par le biais d'Internet, à la galerie d'art UC Davis Gallery, qui les téléchargera, les imprimera et les encadrera. Ce projet anticipe le fonctionnement des musées à l'âge électronique.

Peut-on visualiser le fonctionnement des soins infirmiers à l'ère électronique? Je n'en doute pas si nous articulons l'avenir technologique autour de l'axe fondamental du toucher réconfortant. Au début des années 1980, Fritjov Capra (1982) a défini sa vision des soins infirmiers comme étant une force sociale. Il anticipait un nouveau système de soins de santé primaires:

[faisant l'objet] aujourd'hui d'une promotion vigoureuse par les infirmières qui se trouvent aux premières lignes du mouvement des soins de santé intégrés... Ces infirmières excellemment formées et fortement motivées seront les mieux placées pour assumer les responsabilités de l'éducation sanitaire, des consultations et des soins préventifs (p.414).

Gretta Styles (1989), ancienne doyenne de la UCSF School of Nursing et ancienne présidente du CII, avance:

Notre opinion sur l'importance sociale des soins infirmiers repose dans une large mesure sur une conception claire des soins infirmiers – de leur valeur sociale; de leurs réalisations passées, présentes et futures. En un mot, nous avons une "vision", une qualité qui est source d'orientation interne et d'inspiration externe (p.124).

Il y a dix ans, ma collègue Kathy Oberle et moi avons publié un article qui fait encore partie de mes préférés (Davies et Oberle, 1990). Nous y décrivions un modèle de soins infirmiers de soutien. Ce document avait son origine dans les discussions que j'avais eues avec Alice Weinlick qui était alors infirmière clinicienne au Cross Cancer Institute d'Edmonton. Un jour, Alice m'a fait part de la frustration qu'elle éprouvait à remplir les rapports hebdomadaires exigés. Elle constatait que les jours où elle avait l'impression d'avoir accompli peu de choses, elle avait beaucoup de données à y inscrire - nombre d'appels téléphoniques, de consultations, d'aiguillages. Par contre, pour les jours où elle sentait qu'elle avait fait la différence dans la vie de quelqu'un, elle n'avait que peu de données à y consigner. Nous avons décidé de voir si nous pourrions expliquer cet état de fait. Le résultat? Une conceptualisation des soins infirmiers, applicable non seulement à Alice, mais aussi à de nombreuses infirmières œuvrant dans bien des milieux, comme nous l'avons appris depuis.

Les soins infirmiers ne peuvent être dissociés de la valorisation. Les infirmières établissent des liens avec les patients et leurs proches, les amènent à prendre eux-mêmes le contrôle, les aident à donner une signification à leur situation et posent les actes que ces derniers ne peuvent poser eux-mêmes. Ce modèle

préserve essentiellement l'intégrité du patient et celle de l'infirmière. Les entités personnelles et professionnelles ne sont pas isolées les unes des autres. Comme on le voit, "poser des actes" ne représente qu'une partie des soins infirmiers – celle qui a trait aux procédures, techniques, compétences et au matériel. C'est celle qui met l'accent sur les actes, la méthode et la pratique fondée sur des données probantes. Mais il importe de ne pas oublier que l'infirmière peut "poser des actes" pour les patients sans vraiment établir de relation, sans les aider à prendre le contrôle, ni à donner une signification à leur situation. Nul doute que vous avez toutes démarré une perfusion, changé une poche pour colostomie ou administré des médicaments sans toujours établir un lien avec la personne concernée par l'intervention. Dans de telles situations, vous avez prodigué des soins appropriés et sécuritaires mais il ne s'agissait pas de soins de première qualité. Et malheureusement, c'est ce genre de soins que l'on dispense de plus en plus souvent dans notre système de santé où un effectif infirmier trop réduit doit accomplir un trop grand nombre de tâches. Et que se passe-t-il quand la partie "actes" des soins infirmiers reste à l'avant-plan? Je suppose que cela ne constitue pas un problème pour les infirmières qui croient qu'il s'agit là de la nature réelle des soins infirmiers. Mais pour celles de nous qui pensent que les soins infirmiers sont basés sur des interactions humaines et des liens, le problème est de taille. Nous éprouvons une dissonance cognitive entre notre conception des soins infirmiers et leur état actuel. Comment réagir? Soit nous quittons le domaine des soins infirmiers parce qu'il nous est impossible de réconcilier la dissonance. Soit nous restons et adoptons le mantra culturel. Nous arrivons à nous convaincre que nous agissons vraiment du mieux que nous le pouvons, que nous prodiguons des soins appropriés et sécuritaires et que c'est là tout ce qui compte. Nous contribuons ainsi au système que nous critiquions jadis et que nous nous étions promis d'améliorer au nom des patients que nous soignons et que nous considérons également dans leur globalité. Pourtant, il existe une autre réaction possible, plus efficace. C'est celle qu'Hathaway (1943) a formulé en écrivant:

C'est à ce moment-là que je me suis inventée cette règle que j'appliquerai à toutes les décisions que j'aurai à prendre à l'avenir. Je devais trier les arguments et les classer selon qu'ils se rapportent à la peur ou à la créativité; ensuite, les autres choses étant égales, je devais prendre la décision à laquelle était associé le plus grand nombre d'arguments. Je crois que c'est une règle de ce genre qui amène les jonquilles et les crocus à percer la boue froide.

Et qui fait fleurir les roses après l'hiver.

Lorsque nous nous mettons en quête de données probantes pour la pratique infirmière, ne nous limitons pas aux interventions

"techniques". Concentrons aussi notre attention sur cette partie des soins infirmiers qui ne se mesure pas aisément – tout comme la beauté d'une rose – qui, elle, symbolise les contributions incommensurables de la douceur du toucher, le mot qui rassure, la relation entretenue sur une longue période, l'authentique souci pour le bien-être de ses patients et collègues, la croyance selon laquelle la qualité de vie est quelquefois plus importante que la quantité. Exigeons des données probantes qui montrent qu'un contact humain d'une grande adresse exerce des effets positifs sur la santé et qu'il la favorise. La technologie n'aide pas les gens à faire preuve de leur humanité dans différents contextes, mais si les soins infirmiers favorisent l'aspect humanité, que l'on rassemble des données probantes à ce sujet. S'il nous faut établir le bien-fondé de notre argument, recueillons les données nécessaires. Un aîné des Premières Nations réputé pour ses qualités de pêcheur s'est vu demander comment il se faisait qu'il attrapait toujours davantage de poissons que les autres. Il s'est contenté de répondre: "Je pense comme les poissons". À nous de faire la même chose! Ne pensez plus comme des infirmières mais comme des consommateurs de soins infirmiers. N'essayez pas d'imaginer ce que vous pouvez faire pour les patients, mais ce que vous aimeriez que les infirmières fassent pour vous si vous étiez des patientes ou des proches. Imaginez les attentes que vous auriez des infirmières – voilà une bonne manière d'élargir notre vision.

Envisageons les soins infirmiers comme un voyage d'exploration dont le but n'est pas tant de découvrir de nouveaux panoramas mais de les voir avec le cœur. Chérissons les moments de communion et d'inspiration. Souvenons-nous que la signification des choses émerge quand on les regarde sous des angles différents. Notre formation nous a apprises à être objectives, à nous qui sommes chargées de la collecte et de l'utilisation des données probantes. Mais la signification ne se découvre pas de loin. Notre quête de connaissances ne doit pas dépendre de ce qui se mesure avec des règles. Incorporons-y aussi la rose. Et comme dans la célèbre chanson de Seals & Croft [traduction libre]:

*Éternelle comme la rose
la vraie manière de vivre, j'imagine
Forte, d'une générosité sans fin
Sa raison d'être, son but, constants
Fleurir au jour le jour
Éternelle comme la rose*

Assurons-nous que notre vision des soins infirmiers incorpore l'idée de service, pas en tant que technique, mais comme relation entre deux êtres humains qui allient leurs forces individuelles. Plutôt que de nous voir comme autant de spécialistes réglant des problèmes, imaginons-nous comme des "tisserandes" de relations

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Cancer nursing: Weaving the tapestry for our second century

By Connie Henke Yarbro

Editor's note

This paper was presented as the closing keynote address at the 2000 CANO conference in Victoria, B.C.

It is an honour and a privilege to have been invited to give the closing address for your twelfth annual national conference on "Weaving the new tapestry for oncology nurses: Our future is now."

I am sure each of us has a mental picture of a tapestry. I think of the many beautiful tapestries, truly works of art, in museums around the world, tapestries of heavy cloth woven with rich, varicolored designs, scenes from history, stories from our past. Some hang in tatters, scarred by the passing of time, but even so they maintain their beauty, symbols of glorious days gone by. The dictionary speaks of tapestry as "heavy," and "handwoven," and "complex." The making of a tapestry has been called a "collective art" because it combines the talents of the designer, the painter, and the weaver. When one logs on to the Internet, tapestry relates to land, time, music, food. What we have been relating to in the past few days is the "tapestry of cancer nursing." Nursing, like a tapestry, is a collective work of art that requires the input of many. The warps of cancer nursing stretch throughout our history like the threads of the fabric web that support a tapestry - caring, commitment, cooperation, a dedication to learning, to discovering what is new. On this foundation, each of us weaves our own individual weft, our own individual contribution which, collectively, paint the full picture of our time. Alone, we are a tiny thread. No weft thread carries the full widths of the tapestry. Collectively, however, we are the tapestry. Here today, we are creating new masterpieces for the future. Consider the cancer nurses' tapestry of the past century. Were those nurses not weaving the threads for our own future?

Over 100 years ago, Florence Nightingale said, "Unless we nurses are making progress every year, every month, every week, nursing will go backwards. No system shall endure which does not march" (Nightingale, 1969). The tapestry begins. The "nurse in white" emerged in the early 1900s when nurses were trying to dissociate themselves from the profession's previous drunken and unkempt image. Until then, nurses had worn dark colours characteristic of military and religious roots. Nurses began establishing their professional organizations.

At the turn of the century, cancer was an incurable disease. The death rate was 90% and many people thought it was contagious. Sources of information about nurses in cancer care were minimal in those early years. The Nursing Studies Index lists only 16

articles related to cancer between 1900 and 1930 (Henderson, 1972). Nurses wrote three of these articles. These nurses added their stitches to the tapestry of nursing. Rice (1902) stated, "While cancer has not yet been classed with the transmissible diseases, there are authentic cases where a wife has been infected with cancer by her husband and vice versa" (p.89). This belief was so common that some nurses refused to care for patients with the disease.

In 1906, Charles Plumley Childe, a British physician, wrote the first book to inform the public about cancer: **The control of a scourge** (Ross, 1987). It is of interest that the word cancer was not used even at a time when hospitals for cancer patients existed and the organizational fight against cancer was beginning.

Cancer nursing in the early 1900s was primarily concerned with bedside care and comfort measures for surgical patients (Yarbro, 1996, 1998). The majority of cancer patients presented with advanced cancer and nurses had to develop creative ways to handle the numerous difficulties encountered. In 1915, Tucker discussed caring for a patient with bladder and rectal fistulas as a result of pelvic cancer (Tucker, 1915). Pads were not thick enough to prevent the bed sheets from getting wet. She improvised by using an air cushion with newspapers underneath and muslin wrapped around the cushion and newspapers. When soiled, only the muslin needed cleaning, which meant a great saving on laundry expenses. As a home nurse, she was provided a budget to carry out her work but was expected to save as much as possible. In those early days, there were considerable delays in detection and treatment of cancer. Examples of medical misinformation sound shocking today: a woman with breast cancer was told by her physician to "wait until it begins to bleed and then come back, and I will tell you what to do." Bleeding of a cancerous uterus was ascribed to "a return of menstruation," "rheumatism," or "a cold in the pelvis." Other common sayings were, "It is your menopause," "Don't bother it till it bothers you," and "Go home and forget about it" (American Cancer Society, 1924-1925).

During the 1930s and 1940s, documentation of cancer nursing practice and care was still minimal. Cowan (1934) noted that cancer nurses need to pay attention to pain control and the mental needs of patients. Colonic irrigations of a salt solution were used to treat patients with colon cancer. The role of the radiation therapy nurse was described by Hopp (1941) who noted that no special routine was followed in caring for patients with cancer and efforts to alleviate side effects of nausea and vomiting had not been successful. Lemon juice, sour wine sipped slowly, and ginger ale were used for nausea, vomiting, and anorexia.

The first half of the 20th century is noted for the use of ionizing radiation in the diagnosis and treatment of cancer and the extension of surgical procedures. Progress was made by surgeons and radiotherapists, but it was the nurse who provided the care and comfort (Yarbro, 1998). Think about the conditions under which those nurses worked. Think about the advantages we have today.

The second half of the century is noted for significant progress in systemic chemotherapy, further progress in radiation therapy, multimodality therapy, and an increased understanding of cell biology. Cancer nurses at major institutions of cancer care developed innovative programs to provide care to cancer patients. Exercise classes to piano music were held for patients with breast cancer who had radical mastectomies, the procedure of colostomy irrigation was developed, and tube feeding was considered technology at its best! (Yarbro, 1996).

By the late 1950s, the nursing profession began to be concerned with educational preparation and about who we were and what we

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should be doing. Changes in nursing practice and scientific advances expanded and extended nurses' roles. There was a critical need to provide expert, technically complex nursing care at a time that technology in health care was exploding and also at a time when a general nursing shortage existed, thus the role of the clinical nurse specialist was developed (Yarbro, 1996, 1998).

By the late 1970s and '80s, oncology nursing as a specialty was internationally recognized and nurses were expanding their roles to all aspects of cancer care (Yarbro, 1998). Oncology nursing societies were established: the Oncology Nursing Society in the United States in 1975, the Royal College of Cancer Nursing Society in 1978, and the Canadian Association of Nurses in Oncology in 1985. The first International Conference on Cancer Nursing was held in 1978 in London. The establishment of the International Society of Nurses in Cancer Care (ISNCC) in 1984, the emergence and progress of cancer nursing research, the proliferation of educational programs, cancer nursing literature, and the development of standards and guidelines for cancer nursing services and cancer nursing education are just a few milestones on the road of progress in cancer nursing. The decade of the 1990s paved the way for our entry into the 21st century. The last five years of the 20th century witnessed more dramatic progress in cancer treatment than the first 95 years.

Throughout the history of cancer nursing, nursing leaders encountered problems and challenges but moved forward by taking advantage of the opportunities at hand. I believe that we will do no less! However, we confront an even greater challenge because the problems and issues facing us today go beyond bedside care. These challenges concern health care systems, complex questions of ethics and problematic economics, and new nursing roles. I believe the changes happening today are

providing exciting new opportunities for nurses. In his keynote address yesterday, Ken Stratford reminded us to embrace change, be flexible and that we are the "change agents." Thus, we do have the opportunity to be a strong force in the 21st century.

The physician-dominated, illness-focused, hospital-based, health care model will be replaced by preventive, community-defined, collaborative health care. Nurses will have expanded opportunities for new independent and interdependent roles (Orchard, Smillie, & Meagher-Stewart, 2000). But as health care changes, we will have to change with it. And, the question is - how do we do this? What challenges will we face? How should nursing evolve in the changing health care environment? What must we do to create a preferred future for nursing? A preferred future is what we want to happen. What threads must we place into the tapestry of our profession to draw the picture of what we want nursing to be, to make nursing what it should be? What threads will **you** add to our tapestry? Let us look at some areas where you can make significant contributions to our tapestry.

We are learning how to prevent most cancers. Nurses must lead the way in cancer prevention effort. Even though we have made incredible progress in cancer care, cancer is forecasted to be the number one cause of death in my country [USA] within 10 years. Worldwide, cancer cases are expected to reach 20 million new cases by 2020. Seventy per cent of these cases will be in developing countries (WHO, 1999). We are fortunate to have the resources we have. Nurses in developing countries who creatively work to provide prevention and care with minimal resources constantly amaze me. They are adding their contributions to our tapestry as well. Life expectancy will double over the next 20 years in many developing countries. Indeed, cancer is a world

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health concern. Therefore, cancer prevention must be a part of our tapestry. We cannot speak of prevention without thinking about tobacco.

The 20th century has been the cigarette century with a tremendous surge in smoking, especially during the 1930s through the 1980s, and as you know the increase in lung cancer deaths corresponds with this surge in smoking. Tobacco is the cause of one out of every seven cases of cancer and four million deaths annually worldwide (WHO, 1999). By 2020, tobacco use will be killing more people than any single disease. Trends in per capita consumption indicate that smoking is high in high income countries, but as midlevel income countries become more westernized, smoking increases. It is a worldwide concern as evidenced by antismoking posters and other advertising developed by many different countries.

Nothing kills like tobacco. Cigarettes kill more Americans than AIDS, alcohol, car accidents, fires, cocaine, heroin, murders, and suicides combined (U.S. Department of Health, 1990). Cancer control objectives are aimed at reducing the number of smokers, particularly among youths and young adults. Restrictions on advertising, smoking cessation programs, prevention programs targeted to grade school children, and increasing tobacco taxes are some of the current efforts underway. Labeling requirements for cigarettes vary from country to country. The United States' regulations fall short of some other nations. Poland has laws requiring labeling equivalent to the current 30% front panel coverage required by Canada (Miller, 2000). New proposed labeling regulations in Canada require that deterrent messages cover 60% of the front panel of cigarette packages. These messages have never been tried before. Hopefully, this education will help reduce smoking rates.

The taxes on cigarettes in major industrialized nations are quite variable. The highest cost in Canada is in Newfoundland and the lowest cost is in Ontario (Mitka, 2000). Canada reported that teen smoking declined by more than 60% between 1981 and 1991 in association with raising tobacco taxes, but smoking among Canadians age 15-19 rose from 21% to 28% during the 1990s (Miller, 2000). Laws alone will not accomplish our goal. Only social pressure, peer pressure, will work.

We have, in America, been far more successful at decreasing smoking by physicians than we have for nurses. Why is that? When nurses smoke, can we expect our patients to abstain? Nurses should lead the way in setting the social standard of a smoke-free society. The ISNCC has addressed this through its position statement on tobacco and health, and is in the process of establishing an International Coalition of Nurses Against Tobacco. Who better than cancer nurses to move forward in this area? A collaborative effort by many organizations, including yours [CANO], will help us move towards a smoke-free society in the 21st century.

Advances in science and technology are a major part of our tapestry today and in the future. The advances in cancer treatment that develop at a rapid pace in the 21st century will be selectively targeted to genes and individuals. For the first time in the history of cancer care, we stand on the threshold of specific treatments based on known alterations in the genetics of the cancer cell and on individual genetic differences (Yarbro, 1998). We are entering an era when disease will be predicted before it occurs, and treated specifically when it does occur. Nurses will need to acquire knowledge in biology, immunology, and genetics that serves as a foundation for this new understanding. The old pattern of chronic disease is shifting to a new pattern that focuses on prediction and specific management of illness. Health promotion and prevention will finally become an increasingly more important aspect of our care, a continuing thread in the tapestry of cancer nursing.

The Human Genome Project has been completed four years earlier than predicted. This worldwide collaborative project has

mapped and sequenced the estimated 50,000 genes that make up the human genome, including the genes responsible for cancer. Some of these have already been identified. As a result of the advances in genetics and molecular biology, we will soon understand the steps needed to alter the biology of cancer. We will identify high-risk groups and better target our cancer prevention and treatment. Now imagine yourself just a few years from now. A new line of drugs will be available. You will need to explain treatments to your patients using an entirely new vocabulary. You will be asked to deal with quite different toxicity spectra. The same DNA technology that showed where O.J. Simpson was will be applied to stool, and blood, and sputum to tell us where cancer is.

Nurses are already encountering a human dimension of cancer genetics. The popular test for the breast cancer gene BRCA1 provides information that gives women many options. While the gene apparently confers an 85% risk of developing breast cancer and a 40% to 60% risk of ovarian cancer, women who test positive may reduce that risk. Some women adopt a program that includes low fat diet, exercise, and avoidance of estrogen after menopause, and some even opt to have prophylactic mastectomies and have their ovaries removed. How do you respond when a patient asks about her risk? What about the 30-year-old woman whose biopsy has just revealed breast cancer and she asks you, "What does this mean for my daughter?" Cancer nurses are going to need to understand cancer genetics. Especially when one considers that 20 years from now, most cancers may have gene therapy as part of their treatment. Cancer nurses must master the language of genetics and respond appropriately to questions patients will ask.

Ethical issues will increase as a result of these advances and will be a major part of nursing responsibilities. As you know, cloning, genetic testing, and assisted suicide are the issues we are facing today and this will continue in the world of biological politics. Genetic testing is already raising a number of ethical and legal questions. For example, can the results of these tests be used by insurance companies and employers to identify people who might be occupational risks? How do we keep this information private? Should anyone be tested before the age of consent? The ethical dilemmas of life and death will increase. Do individuals have the right to die? Or do they have a duty to die if their prognosis is poor and they are elderly? Tranmer's presentation stressed that nurses must assume a professional role in the end-of-life care.

What about health care rationing? The demand for health care is limitless and there has always been and will continue to be some system of rationing. As technologies proliferate and costs escalate, the issue of rational and equitable distribution of health care goods to our population will continue. The question is, "Who will control the system of rationing?" Further, who should have access to which resources and technology? If you smoke, who should pay for the damage to your health? The way we answer these questions, the way we take a leadership role in speaking out on these issues, the way we ensure the rights of our patients, the way we work collaboratively with other health care professionals, all of these will paint a picture on the tapestry of 21st century cancer nursing.

The changing consumer is another of the challenges we have in weaving the tapestry of cancer nursing. The future consumer of health care will be dramatically different than the consumer of today. The public is more assertive, better informed, and concerned about health care choices.

As a result of remarkable gains in life expectancy across the world, the elderly population will reach 423 million this year, with 250 million living in developing countries (WHO Study Group, 1994). With the majority of cancers occurring in patients over 65 years of age, this century will encounter an increase in demand for treatment of cancer. This demand is of great concern to us in the United States, where 76 million baby boomers will start to retire in 2011. The

demand already exists today. For example, we know that one-third of health care consumption is by the elderly; the majority of hospital admissions involve the elderly; most elderly care is given by the family; the majority of the elderly fail to take medications properly, and there is an increasing number of individuals leaving jobs to assume caregiving responsibilities. During our second century of cancer nursing, geriatrics will be a major focus in oncology and a required part of medical and nursing education. Additionally, more informal caregivers will be needed. Nurses must interact more closely with the family members and these informal caregivers by developing creative programs that will allow the multidisciplinary health care team to collaborate closely with these caregivers (Yarbro, 1998).

The cancer survivor is increasingly at the forefront of public awareness. Patient advocacy groups that once were fairly general are now arising as specialty support groups with a powerful voice and are making an impact on legislation and sources of funding. One out of five people will still get cancer, two out of three cancer patients will be cured in the 21st century, and one out of 1,000 individuals reaching the age of 20 will be a survivor of childhood cancer. We have a population of children and adolescents that will continue to need follow-up care as they age. Living with long-term effects from cancer therapy and screening for second or third malignancies will require astute assessment, psychological support, and numerous rehabilitative efforts.

Consumers of health care are demanding affordable, safe, and comprehensive care. They are discharged earlier from the hospital, earlier and sicker, and waiting for treatment. Many are told to take on new responsibilities for self-care and they are not ready. Florence Nightingale would be delighted with this movement to self-care and autonomy. Over a century ago she said, "Whatever a patient *can* do himself, it is better" (Nightingale, 1969). The nurse must be at the forefront of teaching patients how to cope with the burdens of self-care.

Individuals, families, and communities will play a larger role in determining and meeting their own health needs. The electronic Internet has helped patients make contact with fellow cancer patients and learn about their disease and treatments. Web research has transformed the visit to the doctor. With an estimated 100,000 medical websites, patients can look up any disease, drug, or medical condition in seconds. It is quite common for a patient to arrive for treatment with a copy in hand of a new therapy being tried at another institution or suggestions on how to handle a specific toxicity. The Internet has numerous listings for cancer support groups, some of which relate to specific cancers, e.g. prostate and breast cancer. The information age has provided an important medium for nurses in providing support and education.

Today, more than 400 million people are users of the Internet and the number is expected to continue to increase (Anon., 2001). We cannot ignore the change. As McIntosh and Rizzo noted in their presentation on "Face to face with technology: Implications for nursing practice," nurses must learn to manage technology - or they will end up being managed by technology.

It seems apparent that we are undergoing some form of health care revolution in each of our countries. I am not an authority on your system, but I believe we have some similarities. Yesterday, the newspaper reported that health care costs will rise 6 to 9% a year over the next decade. In his presentation, Stratford noted that Canada will reinvent the health system. We too are evaluating changes for our system. In the USA, we are facing the challenges of a managed care environment, hospital closings, shifts in health care delivery from the hospital to the outpatient setting and to the home with more acutely ill patients in these environments, elimination of registered nurse positions and their replacement with unlicensed assistive personnel, the replacement of specialty care by primary care, changing roles, and lack of qualified or experienced nurses for oncology care.

What is most alarming for nurses around the world is the nursing shortage. Nursing shortages exist nearly everywhere - it is one of the greatest challenges of this century. We are seeing more migration of nurses as they seek higher salaries and better working conditions. For example, in the United Kingdom where there is an acute nursing shortage, the number of overseas nurses coming to the UK has risen by 48% in 12 months. Most recruits are from South Africa, Australia, the Philippines, New Zealand, and the West Indies (WHO, 2000).

You must be just as concerned in your country. Nurses under the age of 35 decreased by 21% between 1994 and 1999. And your nurses are getting older, with 43 being the average age of a Canadian registered nurse (SEW News, 2000). We heard from several presenters that the nursing school enrollment has dropped and by 2011 there will be a shortage of 113,000 nurses. We also have a shortage of nurses and physicians. As I age, I wonder who will take care of me. At a recent worldwide conference, Judith Oulton, executive director of the International Council of Nurses (ICN), noted that this century will see the rise of a global professional nurse, an individual qualified to provide services anywhere. As the recruitment and retention crisis expands, the nursing profession must act. Our education systems must act. And as a cancer nurse, no matter where you work and no matter at what level, you can be a collective part of the tapestry of cancer nursing by being a mentor. I would venture to say that each of you in this room has mentored another nurse. Sometimes you did it without even knowing you did it. In my brief observations over the past two days, I have witnessed or heard stories of mentorship. Even some interesting recruitment stories! On Monday, Leahy and colleagues described their initiatives to prepare inexperienced nurses in the specialty of oncology. One aspect was a mentorship program where every nurse who comes to the centre is connected with a mentor. Fitzsimmons reminded us that "caring leadership" is a key to recruitment and retention. I would challenge you to make a concerted effort to serve as a mentor. By nurturing, by influencing, the life of one nurse, the lives of many people are affected.

As we weave, we must not forget the warps of nursing that permit us to each provide a weft of thread for our tapestry. Our foundations guide what we can and must do. Our foundation is nursing and care.

Nurses are the largest health care provider group in virtually all countries. Even though we encounter nursing shortages, there are 11 million working nurses around the world and 80% of all primary health care is delivered by nurses (ICN, 2000).

Nurses improve the quality of care in hospitals. Research has shown that when you have more nurses you will have shorter lengths of stay, lower costs, and fewer complications (Prescott, 1993). A higher ratio of nurses to patients in hospitals revealed six fewer deaths per 1,000 patients than hospitals with fewer RNs (Hartz et al., 1989).

We have seen a change in what consumers think about nurses. Consumers have confidence in nurses. A recent poll of the public indicated that 86% were willing to go to an advanced practice nurse for basic health care. Nurses are respected more than any other health care provider and the majority of Americans indicated that registered nurses are not given responsibilities equal to their abilities (Brown & Grimes, 1993), and the primary care provided by nurse practitioners is equivalent or superior to that provided by physicians (U.S. Congress, 1986).

Diversity in nurses' roles can strengthen our tapestry, as each role provides different stitches to provide a unique pattern and story. I believe the diversity in roles is exciting. No longer is it just hospital nursing, but we have moved care to a variety of settings. We have heard many papers describing creativity in education, nursing roles in the community, the nurse researchers who are providing tools, instruments, and evidence for our practice. We have heard discussions about the various advanced practice roles and primary nursing. When I was perusing the Canadian Nurses Association (CNA) website related to issues and trends in Canadian nursing, I came across several interesting papers. Suggestions for the community nurse, advanced

practice nurse, and even the nurse entrepreneur; all excellent resources. These diverse roles are strengthening the tapestry.

Those of us who entered the nursing profession entered with a caring spirit. No matter what path you take during your nursing career, I do not believe that the pattern of caring disappears.

I noted in a recent article (Yarbro, 1998) that this is a time, the beginning of a new century, when numerous authors are writing about the future of everything. And nursing is no exception. Some are optimistic, some are pessimistic. I am an optimist. I believe that the dramatic changes taking place present many opportunities for nurses in this millennium. Yes, we need to improve our nursing education system to meet the changing environment of the future. Yes, we need to reach consensus about our various nursing roles and the appropriate education and training for these roles. Yes, we need to be proactive rather than always complaining. We need to support our peers and work collaboratively with our physician colleagues. Yes, we need to inform the public about who and what we are. In an eloquent article, Kitson (1997), noted that as nurses we need new metaphors and new images to communicate our essence. She suggested a slogan, "We will be there for you." I have no doubt that we will be there for our patients, no matter what happens. I believe that we are changing the concept of the nurse that is held by the public. Our image is changing.


"Nurses always there for you" was the slogan for International Nurses Day. On Monday, we heard the CNA slogan for 2001 nurses week: "Nurses: Champions for Health." Your president challenged you to "Honk, raise your voices to what you have accomplished. Be the voice of cancer nursing in Canada."

Janes and Robinson reminded us on Monday that cancer nurses

can make a difference, when they so eloquently and creatively reminded us that cancer is an uninvited guest to the family, and children need to be a part of the picture early. We must make the children a part of the collective work of our cancer nursing tapestry.

The presentations over the last three days are a clear indication that we are making a difference in cancer patient care in palliative care, symptom management, patient education, the treatment settings such as radiation therapy, bone marrow transplant, pediatric oncology, and even developing creative programs in urgent care and the community. The strength of nursing research has been a strong thread throughout the conference. It is up to us to show that we make a difference, that we are cost-effective, that we provide quality care.

We are "the continuous thread of patient care." We leave this conference and will return to our settings, hopefully with renewed commitment, energy, excitement to continue the tapestry we are creating. The individual contributions at this conference are the collective work of art that is creating and will continue to create the tapestry of cancer nursing.

As nurses and citizens of the world, we are creating the future by what we do or do not do today. All of us look with pride on the tapestry of nursing created by our predecessors. Let each of us, in the small weft we weave into our own part of the tapestry, always remember that those who follow will look someday at what we have done. May they see no imperfection in our work, be it ever so tiny. The tapestry we weave for our world of the 21st century is bound only by our visions, our values, our resources, and our imaginations. 

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Tisser la tapisserie des soins en cancérologie à l'aube du deuxième siècle de notre histoire

Par Connie Henke Yarbro

C'est un honneur et un privilège pour moi d'avoir été invitée à prononcer le discours de clôture de votre douzième conférence nationale annuelle ayant pour thème "Tisser la nouvelle tapisserie des soins infirmiers en oncologie: notre avenir se décide maintenant!".

Je suis sûre que vous avez toutes en tête l'image d'une tapisserie. Moi, je pense aux nombreuses tapisseries conservées dans les musées du globe, de véritables œuvres d'art. Ces lourdes tapisseries de toile agrémentées de motifs élégants et multicolores, de scènes historiques, de récits du passé. Certaines, en lambeaux, ont souffert le passage du temps, ce qui ne les empêche pas de conserver leur beauté et de symboliser encore aujourd'hui la gloire des temps passés. Les dictionnaires attribuent divers qualificatifs aux tapisseries: "épaisses", "tissées à la main" et "complexes". On décrit la production d'une tapisserie comme étant un "art collectif" parce qu'elle allie les talents du concepteur, du peintre et du tisserand. Quand on fait une recherche sur ce thème dans Internet, le terme tapisserie se retrouve dans le contexte de la terre, du temps, de la musique et de l'alimentation. Quant à nous, notre perspective, au cours des dernières journées, a été la "tapisserie des soins infirmiers en oncologie". À l'instar d'une tapisserie, les soins infirmiers sont une œuvre d'art collective qui exige les contributions d'un grand nombre. Tout au long de notre histoire, les fils de la chaîne des soins infirmiers en oncologie tissent notre histoire en s'alliant à ceux de la trame qui les soutiennent – sollicitude, engagement, collaboration, soif de connaissances, passion des découvertes. Chacune de nous tisse, sur cette fondation, sa trame individuelle, sa contribution personnelle qui s'ajoute aux autres pour former le tableau complet de nos réalisations actuelles. Prises individuellement, nous ne sommes que des fils ténus. Mais aucun fil de la trame ne soutient à lui seul l'entière largeur de la tapisserie. Prises collectivement, en revanche, nous constituons la tapisserie. C'est ainsi qu'aujourd'hui, nous créons les nouvelles œuvres d'art de demain. Penchons-nous sur la tapisserie des infirmières en cancérologie du siècle dernier. Ne tissaient-elles pas les fils de la trame de notre propre avenir?

Il y a plus de cent ans, Florence Nightingale a déclaré: "À moins que les infirmières ne continuent de progresser chaque année, chaque mois, chaque semaine, les soins infirmiers régresseront. Aucun système ne survit s'il ne va pas de l'avant" (Nightingale, 1969). Remontons donc à la naissance de la tapisserie. C'est au début des années 1900 que l'image de l'infirmière vêtue de blanc émerge, dans le but de se démarquer de l'ancienne réputation d'ivresse et de désordre que s'étaient "mérité" nos consœurs. Car jusqu'alors, les infirmières portaient des vêtements sombres reflétant les origines militaires et religieuses de notre profession. Puis les infirmières ont commencé à mettre sur pied des organismes professionnels.

Au tout début du siècle, le cancer était une maladie incurable. Le taux de mortalité s'élevait à 90 % et bien des gens croyaient qu'il était

contagieux. Les sources d'information sur les infirmières œuvrant en cancérologie sont rares durant ces premières années. Ainsi, le Nursing Studies Index ne donne que 16 articles sur le cancer pour la période 1900 - 1930 (Henderson, 1972), dont trois rédigés par des infirmières. Ces infirmières ont ajouté leurs points à la tapisserie des soins infirmiers. Et Rice (1902) d'écrire: "Bien que le cancer n'ait pas encore été classé parmi les maladies transmissibles, il existe des cas authentiques où l'épouse a attrapé le cancer de son conjoint et vice versa" (p.89). Cette croyance était si répandue que certaines infirmières refusaient de soigner les patients qui en étaient atteints.

En 1906, Charles Plumley Childe, un médecin britannique, a écrit le premier livre sur le cancer destiné à l'éducation du public: **The control of a scourge** (Ross, 1987). Il est intéressant de noter que le mot cancer n'était pas utilisé à cette époque alors qu'il existait des hôpitaux pour les patients qui en souffraient et qu'on mettait en branle la lutte organisationnelle contre ce fléau.

Au début des années 1900, les soins infirmiers en oncologie portaient principalement sur les soins de chevet et les mesures de réconfort prodigués aux opérés (Yarbro, 1996, 1998). La majorité des patients étaient atteints de cancers avancés et les infirmières devaient faire preuve d'innovation pour faire face aux nombreuses difficultés rencontrées. En 1915, Tucker détaillait les soins dispensés à un malade atteint de fistules à la vessie et au rectum à la suite de son cancer pelvien (Tucker, 1915). Les tampons n'étaient pas assez épais pour empêcher les draps d'être souillés. Elle a improvisé en utilisant un coussin d'air sous lequel elle a placé des journaux et a emballé le tout de mousseline. Lorsqu'il était souillé, il suffisait de changer la mousseline ce qui économisait bien des dépenses de blanchisserie. À titre d'infirmière de soins à domicile, elle disposait d'un budget pour accomplir son travail, mais on attendait d'elle qu'elle fasse le plus d'économies possibles. En ce temps-là, des délais considérables séparaient la détection du cancer de son traitement. Certains exemples d'ignorance médicale nous choquent aujourd'hui: ainsi cette femme atteinte d'un cancer du sein qui s'est vu dire par son médecin: "Attendez les premiers saignements et revenez me voir, je vous dirai alors quoi faire." Les saignements dus à un cancer de l'utérus étaient attribués à "une reprise des menstruations", aux "rhumatismes" ou à "un rhume au niveau du bassin". On entendait aussi souvent les propos suivants: "C'est la ménopause"; "Ne le dérangez pas tant qu'il ne vous dérange pas"; et "Rentrez chez vous et n'y pensez plus" (American Cancer Society, 1924-1925).

Au cours des années 1930 et 1940, la documentation de la pratique infirmière et des soins infirmiers liés au cancer reste limitée. Cowan (1934) constate que les infirmières en cancérologie doivent se pencher sur la maîtrise de la douleur et sur les besoins mentaux des patients. On utilisait des irrigations coliques à base de soluté salin pour traiter les patients atteints de cancer du côlon. Le rôle de l'infirmière en radiothérapie décrit par Hopper (1941) indique qu'aucune intervention spéciale n'était utilisée pour soigner les patients atteints de cancer et que les efforts visant à soulager les effets secondaires – nausées et vomissements – restaient vains. On se servait de jus de citron, de vinaigre de vin bu à petits coups et de soda au gingembre en cas de nausées, de vomissements et d'anorexie.

La première moitié du 20^e siècle marque l'utilisation des rayonnements ionisants dans le diagnostic et le traitement du cancer et le développement des interventions chirurgicales. Les chirurgiens et les radiothérapeutes réalisent d'énormes progrès, mais ce sont les infirmières qui prodiguent soins et réconfort (Yarbro, 1998). Pensez un peu aux conditions dans lesquelles ces infirmières travaillaient. Réfléchissez aux avantages que nous connaissons aujourd'hui.

La deuxième moitié du siècle se caractérise par les importants progrès réalisés en chimiothérapie systémique, de nouveaux progrès en radiothérapie, la thérapie multimodale et une meilleure

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connaissance de la biologie cellulaire. Les infirmières en oncologie œuvrant dans les grands établissements de cancérologie ont mis sur pied des programmes innovateurs en matière de soins aux malades cancéreux. Des leçons de conditionnement physique étaient organisées au son du piano au profit des femmes atteintes de cancer du sein ayant subi une mastectomie radicale; le procédé de l'irrigation par colostomie a été mis au point, et on voyait dans l'alimentation entérale le nec plus ultra de la technologie! (Yarbro, 1996).

Vers la fin des années 1950, la profession infirmière a commencé à se préoccuper des questions de formation, de ce que les infirmières étaient vraiment et de ce qu'elles devaient accomplir. L'évolution de la pratique infirmière et les progrès scientifiques ont développé et élargi les rôles infirmiers. Un besoin crucial s'est fait sentir, celui de fournir des soins infirmiers spécialisés, d'une grande complexité technique à une époque où la technologie envahissait les soins de santé ce qui, dans le contexte de la pénurie générale de personnel infirmier qui existait alors, a entraîné le développement du rôle de l'infirmière clinicienne spécialisée (Yarbro, 1996, 1998).

Dès la fin des années 1970 et 1980, les soins infirmiers en oncologie étaient reconnus comme spécialité à l'échelle internationale, et les infirmières étendaient leurs rôles à l'ensemble des aspects des soins aux personnes atteintes de cancer (Yarbro, 1998). Des organismes de soins infirmiers en oncologie ont été fondés: la Oncology Nursing Society aux États-Unis en 1975, le Royal College of Nursing Cancer Nursing Society en 1978 et l'Association canadienne des infirmières en oncologie en 1985. C'est en 1978, à Londres, que s'est déroulée la première conférence internationale sur le cancer. Quelques-uns des principaux jalons des progrès des soins infirmiers en cancérologie sont l'établissement de la International Society of Nurses in Cancer Care (ISNCC) en 1984, la naissance et le développement de la recherche infirmière en oncologie, la prolifération de programmes de formation, d'écrits relatifs aux soins infirmiers en oncologie, l'élaboration de normes et de lignes directrices concernant les services infirmiers et la formation infirmière en oncologie. Quant aux années 1990, elles ont préparé notre entrée dans le 21^e siècle. Il y a eu, au cours des cinq dernières années du 20^e siècle, plus de progrès spectaculaires dans le domaine du traitement du cancer qu'au cours des 95 autres années.

Tout au long de l'histoire des soins infirmiers en cancérologie, les dirigeants infirmiers ont fait face à des défis et à des problèmes, mais ils ont su saisir les occasions qui se présentaient pour faire progresser leur cause. Je crois que nous serons à la hauteur de leur exemple! Pourtant, nous devons relever des défis de taille, car les problèmes et les questions qui se posent aujourd'hui ne se limitent pas aux soins de chevet. Ils concernent les systèmes de soins de santé, d'épineuses questions d'éthique, la problématique du contexte économique et les nouveaux rôles prévus pour les soins infirmiers. Je crois que les changements qui surviennent aujourd'hui offrent de passionnantes possibilités aux infirmières. Dans le discours-programme qu'il a prononcé hier, Ken Stratford nous a rappelé d'embrasser le changement, de faire preuve de souplesse et que nous sommes des "*agents de changement*." Nous avons donc l'opportunité d'être une force puissante au 21^e siècle.

Le modèle de soins actuel dominé par les médecins, axé sur la maladie et privilégiant les centres hospitaliers sera remplacé par un système de soins défini par la collectivité et axé sur la prévention et la collaboration. Les infirmières auront davantage d'occasions de jouer des rôles autonomes et interdépendants (Orchard, Smillie et Meagher-Stewart, 2000). Mais il nous faudra suivre l'évolution des soins de santé. Et les grandes questions restent: comment y parviendrons-nous? Quels défis allons-nous devoir relever? Comment les soins infirmiers doivent-ils évoluer face aux changements agitant le système de santé? Que devons-nous faire pour façonner l'avenir préférable pour les soins infirmiers? Par avenir préférable, j'entends ce que nous souhaitons voir se réaliser. Quels fils devons-nous ajouter à la tapisserie de notre profession pour créer le tableau correspondant à la vision que nous avons des soins infirmiers, et la concrétiser par la suite? Quels fils allez-vous contribuer à notre tapisserie? Examinons

quelques-uns des domaines qui s'ouvrent à vos contributions.

Nous apprenons, de nos jours, à prévenir la plupart des cancers et les infirmières doivent se trouver aux premières loges de cet effort de prévention. Quoique nous ayons réalisé de remarquables progrès en matière de soins aux personnes atteintes de cancer, on prévoit que cette maladie deviendra la première cause de décès dans mon pays [les É.-U.] au cours des dix prochaines années. À l'échelle planétaire, on s'attend à ce que les nouveaux cas de cancer atteignent la marque des 20 millions d'ici 2020. Soixante-dix pour cent d'entre eux se produiront dans les pays en voie de développement (WHO, 1999). Nous avons la chance de pouvoir compter sur les ressources que nous avons. Les infirmières des pays en voie de développement ne cessent de m'étonner par la créativité avec laquelle elles dispensent des soins et font de la prévention avec des ressources négligeables. Elles aussi contribuent à l'élaboration de notre tapisserie. Au cours des 20 prochaines années, l'espérance de vie va doubler dans plusieurs de ces pays. Le cancer est vraiment un problème de santé d'envergure mondiale. La prévention de cette maladie doit donc être intégrée à notre tapisserie. Et on ne peut parler de prévention sans mentionner le tabagisme.

Le 20^e siècle aura été sous le signe de la cigarette, avec la formidable augmentation subite du tabagisme, notamment entre les années 1930 et 1980, qui s'est soldée, comme vous le savez, par une augmentation parallèle des décès par cancer du poumon. Le tabagisme est responsable d'un décès par cancer sur sept et de quatre millions de décès par an à travers le monde (WHO, 1999). D'ici 2020, le tabagisme tuera, à lui seul, plus d'êtres humains que n'importe quelle autre maladie. Sur le plan de la consommation individuelle, les tendances indiquent que le taux de tabagisme est le plus fort dans les pays à revenu élevé et qu'il augmente dans les pays à revenu moyen à mesure qu'ils s'occidentalisent. C'est une préoccupation mondiale comme le prouvent les nombreuses affiches et publicités antitabac élaborées dans bien des pays différents.

Le tabac est un tueur sans pareil. La cigarette tue plus d'Américains que le sida, l'alcool, les accidents de la route, les incendies, la cocaïne, l'héroïne, les homicides et les suicides mis ensemble (U.S. Department of Health, 1990). Les objectifs de la lutte contre le cancer visent à réduire le nombre de fumeurs, particulièrement chez les adolescents et jeunes adultes. Des restrictions en matière de publicité, des programmes de cessation tabagique, des programmes de prévention destinés aux élèves des écoles élémentaires et l'augmentation des taxes sur le tabac sont quelques-uns des efforts fournis actuellement. Les exigences d'étiquetage varient d'un pays à l'autre. La réglementation des États-Unis n'est pas aussi stricte que celle d'autres nations. La Pologne a des lois d'étiquetage semblables à celles actuellement en vigueur au Canada exigeant que 30 % du panneau avant soient consacrés à des mises en garde (Miller, 2000). Les nouvelles règles d'étiquetage proposées pour le Canada exigent que les messages dissuasifs couvrent 60 % du panneau avant des paquets de cigarettes. C'est la première fois que l'on se sert de ce genre de messages. Espérons que cette campagne aidera à réduire les taux de tabagisme.

Les taxes sur les cigarettes sont très variables au sein des grandes nations industrialisées. Au Canada, c'est à Terre-Neuve qu'elles coûtent le plus cher et en Ontario que leur prix est le plus bas (Mitka, 2000). Le Canada rapportait que le tabagisme juvénile avait baissé de plus de 60 % entre 1981 et 1991 à la suite de l'augmentation des taxes sur le tabac, mais que le tabagisme chez les jeunes du Canada de 15 à 19 ans est passé de 21 à 28 % au cours des années 1990 (Miller, 2000). À elles seules, les lois ne suffiront pas à atteindre notre but. Il n'y a que les pressions sociales et la pression des camarades qui donneront des résultats.

En Amérique du Nord, les médecins ont été plus nombreux que les infirmières à arrêter de fumer. Comment l'expliquer? Lorsque des infirmières fument, sommes-nous en droit d'attendre de nos patients qu'ils s'abstiennent? Les infirmières devraient tracer la voie en matière de norme sociale en faveur d'une société sans fumée. L'ISNCC s'est penchée sur la question en publiant un énoncé de position sur le tabac et la santé, et elle met actuellement sur pied une coalition internationale des infirmières opposées au tabac. Qui est mieux placé que les infirmières en oncologie pour faire avancer les choses dans ce domaine? Un effort de

collaboration rassemblant de nombreux organismes dont le vôtre, nous permettra de progresser vers une société sans fumée au 21^e siècle.

Les progrès scientifiques et technologiques représentent une partie importante de notre tapisserie d'aujourd'hui et de demain. Les progrès fulgurants qui seront réalisés au 21^e siècle dans le domaine du traitement du cancer cibleront les gènes et les individus. Pour la première fois de toute l'histoire des soins en cancérologie, nous sommes à la veille de l'utilisation de traitements spécifiques basés sur les altérations génétiques connues des cellules cancéreuses et sur les différences génétiques individuelles (Yarbro, 1998). Nous entrons dans une période où l'on pourra prédire les maladies avant même leur survenue et les traiter de manière spécifique dès leur apparition. Les infirmières devront acquérir, en biologie, en immunologie et en génétique, les connaissances qui étayent ces nouvelles approches. L'ancien modèle relatif à la maladie chronique sera remplacé par un nouveau schéma privilégiant la prédiction et la gestion spécifique du mal-être. La promotion et la prévention de la santé vont enfin devenir des facettes plus importantes de nos soins, des fils continus de la tapisserie des soins infirmiers en oncologie.

Le projet Génome humain s'est terminé quatre ans avant la date prévue. Ce projet concerté d'envergure planétaire a établi la carte et la séquence des quelque 50 000 gènes qui composent le génome humain, selon les estimations, notamment les gènes responsables du cancer. Certains d'eux ont déjà été identifiés. Les progrès effectués en génétique et en biologie moléculaire nous permettront bientôt de comprendre les étapes requises pour altérer la biologie du cancer. Nous cermerons les groupes à risque et cibleront plus précisément la prévention et le traitement du cancer. Imaginez ce qui se passera dans quelques années. Vous disposerez d'une nouvelle gamme de médicaments. Il vous faudra expliquer les traitements aux patients à l'aide d'un vocabulaire entièrement nouveau. On vous demandera de faire face à des spectres de toxicité très différents. Les analyses de l'ADN, qui ont prouvé où O. J. Simpson s'était rendu, seront appliquées aux selles, au sang et aux expectorations et nous diront où le cancer se cache.

Les infirmières connaissent déjà une des dimensions humaines de la génétique du cancer. Le test de détection du gène du cancer du sein BRCA1, d'une grande popularité, fournit des informations qui ouvrent la porte à plusieurs options pour les femmes. Le gène s'accompagne d'un risque de l'ordre de 85 % de développer le cancer du sein et de 40 à 60 % de contracter un cancer de l'ovaire, mais les femmes dont le test est positif peuvent réduire ce risque. Certaines adoptent un programme incluant un régime pauvre en gras, des exercices physiques et l'évitement des œstrogènes après la ménopause; d'autres choisissent même de subir une mastectomie prophylactique et de se faire enlever leurs ovaires. Comment aborde-t-on les questions des patientes sur le risque encouru? Que dire à la femme de 30 ans dont la biopsie vient de révéler qu'elle a le cancer du sein et qui vous demande: "Qu'est-ce que ça veut dire pour ma fille?" Les infirmières en cancérologie vont devoir assimiler la génétique du cancer. Surtout si on considère que dans vingt ans, le traitement de la plupart des cancers aura une composante génétique. Elles devront maîtriser le langage de la génétique et savoir répondre efficacement aux questions posées par les patients.

Les questions éthiques se multiplieront à la suite de ces progrès et représenteront une partie majeure des responsabilités du personnel infirmier. Comme vous le savez, le clonage, le dépistage génétique et le suicide assisté constituent les grandes questions contemporaines et elles ne sont pas prêtes de disparaître dans le secteur de la politique biologique. Le dépistage génétique soulève déjà un certain nombre de problèmes éthiques et juridiques. Par exemple, les résultats obtenus peuvent-ils être utilisés par les sociétés d'assurance et les employeurs dans le but d'identifier les personnes qui pourraient présenter des risques au travail? Comment assurons-nous le caractère confidentiel de ces renseignements? Peut-on faire subir le test à une personne avant qu'elle n'ait atteint l'âge requis pour consentir? Les dilemmes éthiques entourant la vie et la mort vont foisonner. Les individus ont-ils le droit de mourir? Ou ont-ils le devoir de mourir si leur pronostic

est sombre, lorsqu'ils sont très âgés? Dans sa présentation, Tranmer a insisté sur le fait que les infirmières se doivent d'assumer un rôle professionnel en ce qui concerne les soins en fin de vie.

Passons au sujet de la rationalisation des services de santé. Pour ce qui est des soins de santé, la demande est illimitée et il y a toujours eu et il y aura toujours un système de rationalisation ou un autre. La prolifération des technologies et l'escalade des coûts sont telles que la question de l'affectation rationnelle et équitable des biens et services liés aux soins de santé va rester d'actualité. On se demande: "Qui va contrôler le système de rationalisation?" "Qui va avoir accès à quelles ressources et à quelle technologie? Si on fume, qui devrait régler les dommages qu'on inflige ainsi à sa propre santé?" Les réponses que nous apportons à ces questions, le rôle directeur que nous adopterons pour discuter de ces questions, la manière dont nous défendrons les droits des patients, la collaboration que nous entretiendrons avec les autres professionnels de la santé, traceront à eux tous une image sur la tapisserie des soins infirmiers en cancérologie du 21^e siècle.

L'évolution des consommateurs est un des autres défis à relever alors que nous tissons notre tapisserie. Les consommateurs de soins de santé de demain seront radicalement différents de ceux d'aujourd'hui. Le public s'affirme plus volontiers, il est mieux informé et se préoccupe des choix offerts en matière de soins.

À la suite de l'allongement spectaculaire de l'espérance de vie aux quatre coins du monde, les personnes âgées seront au nombre de 423 millions cette année, dont 250 millions dans les pays développés (WHO Study Group, 1994). Puisque la majorité des cancers surviennent chez les patients de plus de 65 ans, les besoins en matière de traitement du cancer vont connaître une augmentation importante ce siècle-ci. Ces besoins nous inquiètent énormément aux États-Unis où 76 millions de "baby-boomers" vont commencer à prendre leur retraite en 2011. La demande existe déjà de nos jours. On sait, par exemple, qu'en matière de soins de santé, les personnes âgées sont responsables d'un tiers de la consommation; que la majorité des admissions à l'hôpital concernent les personnes âgées; que la plupart des soins aux personnes âgées sont prodigués par les proches; que, dans leur majorité, elles ne prennent pas adéquatement leurs médicaments et qu'un nombre toujours croissant d'individus délaissent leur emploi pour assurer des responsabilités liées à la prestation de soins. Durant le deuxième siècle d'existence des soins infirmiers en oncologie, la gériatrie deviendra un pôle important de notre spécialité et fera obligatoirement partie de la formation médicale et infirmière dispensée. En outre, on aura besoin de davantage de soignants naturels. Il faut que les infirmières interagissent plus étroitement avec les membres de la famille et les soignants naturels en élaborant des programmes innovateurs qui favoriseront une collaboration en profondeur entre eux et l'équipe de santé multidisciplinaire (Yarbro, 1998).

La sensibilisation du public aux survivants du cancer s'accroît régulièrement. Les groupes de promotion de l'intérêt des patients qui étaient auparavant d'une nature plutôt générale prennent désormais la forme de groupes de soutien spécialisés qui font entendre leur voix puissante et font sentir leur présence en matière de législation et de sources de financement. Au 21^e siècle, une personne sur cinq développera un cancer, deux malades du cancer sur trois en seront guéris tandis qu'un individu sur 1000 atteignant l'âge de 20 ans survivra à un cancer de l'enfant. Nous aurons ainsi une population d'enfants et d'adolescents qui continueront d'exiger des soins au fil des ans. Leur expérience des effets à long terme de la thérapie anticancéreuse et le dépistage d'une deuxième ou d'une troisième récurrences nécessiteront des analyses en profondeur, un soutien psychologique et de nombreux efforts en réadaptation.

Les consommateurs de soins de santé réclament des soins intégrés sécuritaires et à la mesure de leurs moyens. On leur donne leur congé plus précocement et ils sortent de l'hôpital plus tôt et plus malades et dans l'attente d'un traitement. On demande à beaucoup d'entre eux d'assumer de nouvelles responsabilités en matière d'autosoin, alors qu'ils ne sont pas prêts. Florence Nightingale serait ravie de ce mouvement vers l'autosoin et l'autonomie. N'a-t-elle pas annoncé, il y a plus de cent ans

de cela: “Tout ce que le patient *peut* faire lui-même est une amélioration” (Nightingale, 1969). Pour l’infirmière, enseigner aux patients comment aborder le fardeau de l’autosoins doit être une grande priorité.

Les individus, les familles et les collectivités sont appelés à jouer un plus grand rôle dans la détermination et la satisfaction de leurs besoins en matière de santé. Internet a aidé les patients atteints de cancer à communiquer entre eux, à se renseigner sur leur maladie et sur les traitements offerts. Les recherches effectuées sur le Web ont transformé la visite médicale. Grâce à l’existence de près de 100 000 sites Web de nature médicale selon les estimations, les patients peuvent s’informer, en l’espace de quelques secondes, sur n’importe quelle maladie ou condition médicale ou sur n’importe quel médicament. Il n’est par rare de voir des patients arriver pour leur traitement avec, en main, un document sur une nouvelle thérapie à l’essai dans un autre établissement ou des suggestions sur la manière de composer avec une toxicité particulière. Internet regorge de listes de groupes de soutien pour cancéreux, dont certains se rapportent à des cancers spécifiques tels ceux de la prostate et du sein. L’ère de l’information a fourni aux infirmières un important médium de diffusion de soutien et d’enseignements.

De nos jours, plus de 400 millions de personnes utilisent Internet et on s’attend à ce que ce nombre continue d’augmenter (Anon., 2001). Nous ne pouvons pas nous permettre d’ignorer cette évolution. Comme McIntosh et Rizzo l’ont remarqué dans leur présentation sur le thème “Face to face with technology: Implications for nursing practice”, les infirmières doivent apprendre à maîtriser la technologie – ou elles risquent de voir leur vie professionnelle contrôlée par cette dernière.

Il me semble que le système de soins de votre pays et celui du mien sont tous deux en proie à une révolution d’une forme ou d’une autre. Je ne me spécialise dans le vôtre, mais je crois qu’on peut dégager certaines similitudes. Le journal d’hier signalait que les coûts de santé allaient augmenter de 6 à 9 % par an au cours de la prochaine décennie. Dans sa présentation, Stratford a affirmé que le Canada réinventerait la notion de système de soins. Nous évaluons nous aussi les changements possibles pour notre système. Ainsi, aux États-Unis, nous devons faire face aux défis suivants: régime de soins gérés, fermetures d’établissements, virage vers les soins en clinique externe et à domicile, ces deux milieux accueillant des patients de plus en plus gravement malades, élimination de postes d’infirmières autorisées remplacées par des travailleurs non qualifiés, remplacement des soins spécialisés par des soins primaires, évolution des rôles, pénurie d’infirmières qualifiées ou expérimentées dans le domaine des soins en oncologie.

Le plus grave pour les infirmières des quatre coins du monde est la pénurie de personnel infirmier. Cette pénurie se fait sentir presque partout – c’est un des plus grands défis du siècle. On remarque une migration accrue des infirmières en quête de meilleurs salaires et de meilleures conditions de travail. Par exemple, le Royaume-Uni subit une pénurie aiguë en matière d’effectif infirmier et le nombre d’infirmières venant de l’étranger a augmenté de 48 % en l’espace de 12 mois. La plupart des nouvelles recrues viennent d’Afrique du Sud, d’Australie, des Philippines, de la Nouvelle-Zélande et des Antilles (WHO, 2000).

La situation est tout aussi préoccupante dans votre propre pays. Il y a eu, entre 1994 et 1999, une réduction de 21 % du nombre d’infirmières de moins de 35 ans. En outre, l’âge moyen des infirmières canadiennes, qui se situe à 43 ans, est en augmentation (SEW News, 2000). Plusieurs conférenciers nous ont appris que les admissions dans les écoles de sciences infirmières avaient baissé et que d’ici 2011, la pénurie se chiffrera à 113 000 infirmières. Les États-Unis connaissent également une pénurie de médecins et d’infirmières. À mesure que je vieillis, je me demande qui va prendre soin de moi. Lors d’une récente conférence mondiale, Judith Oulton, directrice exécutive du Conseil international des infirmières (CII), avançait que ce siècle verrait l’émergence de l’infirmière professionnelle internationale, ayant les qualifications nécessaires pour dispenser des soins partout au monde. Il faut que la profession infirmière réagisse face à cette crise de recrutement et de maintien en poste du personnel. Nos systèmes de formation se doivent d’intervenir. Et en tant

qu’infirmière en cancérologie, peu importe où vous œuvrez et le niveau auquel vous travaillez, vous pouvez contribuer à la tapisserie collective des soins infirmiers en oncologie en vous faisant mentor. Je suis prête à parier que chacune d’entre vous dans la salle a déjà fait du mentorat auprès d’une collègue. Parfois, vous l’avez fait sans vous en rendre compte. Les observations succinctes que j’ai pu faire au cours des deux dernières journées m’ont permis de voir le mentorat à œuvre ou d’entendre parler de telles situations. Même des récits de recrutement des plus intéressants! Lundi, Leahy et ses collègues ont décrit les initiatives proposées en vue de préparer des infirmières débutantes à la pratique de notre spécialité. Elles comprenaient un programme de mentorat en vertu duquel chaque infirmière fréquentant le centre est jumelée avec un mentor. Fitzsimmons nous a rappelé que le “leadership emprunt de sollicitude” est essentiel sur le plan du recrutement et du maintien en poste. J’aimerais que vous vous mobilisiez pour faire du mentorat. En favorisant le développement d’une infirmière et en influençant son vécu, vous toucherez la vie de bien des gens.

Tout en tissant, il ne faut pas que nous perdions de vue la chaîne des soins infirmiers qui permet à chacune de nous de contribuer un fil de trame à la tapisserie collective. Nos fondements régissent ce que nous pouvons et devons faire. Les soins infirmiers et la sollicitude sont nos assises.

Les infirmières forment le plus gros groupe de prestation des soins dans quasiment tous les pays. Bien que nous connaissions des pénuries de personnel infirmier, 11 millions d’elles œuvrent de par le monde, et 80 % de l’ensemble des soins primaires sont prodigués par des infirmières (CII, 2000).

Les infirmières rehaussent la qualité des soins dans les hôpitaux. Les recherches montrent qu’un nombre plus élevé d’infirmières se traduit par des séjours plus courts, des coûts moindres et moins de complications (Prescott, 1993). Dans les hôpitaux, un meilleur ratio infirmières-patients s’accompagnait de 6 décès de moins par 1000 patients que dans les établissements disposant d’un nombre inférieur d’infirmières (Hartz et al., 1989).

La perception des consommateurs vis-à-vis des infirmières a évolué et ils font confiance aux infirmières. Un récent sondage du public indiquait que 86 % des gens étaient d’accord pour consulter une infirmière en pratique avancée pour leurs soins de santé de base. Les infirmières jouissent d’un respect supérieur à celui de tout autre professionnel de la santé, et la majorité des Américains estimaient qu’on ne leur donne pas des responsabilités à la hauteur de leurs capacités (Brown et Grimes, 1993) et que les soins primaires dispensés par les infirmières praticiennes sont égaux ou supérieurs à ceux prodigués par les médecins (U.S. Congress, 1986).

La diversité des rôles infirmiers peut renforcer notre tapisserie car chacun d’eux se traduit par un point différent qui dessine, avec les autres, un motif et une histoire uniques en leur genre. Cette diversité des rôles, je la trouve passionnante. Ils ne se limitent plus aux seuls soins infirmiers hospitaliers, mais touchent maintenant divers milieux. Plusieurs articles nous ont décrit l’innovation dans le domaine de la formation, des rôles infirmiers dans la collectivité, des infirmières chercheuses qui élaborent les outils, les instruments et les données dont nous avons besoin pour l’exercice de notre profession. Des débats ont porté sur les divers rôles de pratique avancée et les soins infirmiers primaires. J’ai découvert plusieurs articles intéressants en consultant la section Enjeux / tendances du site Web de l’Association des infirmières et infirmiers du Canada (AIC): des suggestions à l’intention de l’infirmière en soins communautaires, de l’infirmière en pratique avancée au Canada, et même de l’infirmière libérale, toutes d’excellentes ressources. Ces rôles renforcent la tapisserie de par leur diversité.

Nous avons toutes choisi la profession infirmière pour l’aspect sollicitude. Et quel que soit le cheminement qu’on emprunte durant sa carrière, je ne pense pas que cette sollicitude, et le motif qu’elle représente, disparaisse un jour.

J'ai écrit, dans un de mes récents articles (Yarbro, 1998) qu'en ce début de siècle, une foule d'auteurs se prononcent sur l'avenir de tout ce qui nous entoure. Et les soins infirmiers n'y font pas exception. Certains auteurs sont optimistes, d'autres pessimistes. Moi, je me range dans le camp des optimistes. J'estime que les changements spectaculaires qui surviennent offrent de nombreuses opportunités aux infirmières à l'aube du millénaire. Bien sûr, il nous faut améliorer notre système de formation infirmière afin de composer avec l'environnement changeant de demain. Bien sûr, il nous faut nous concerter à propos des divers rôles infirmiers et des études et de la formation qui leur correspondent. Bien sûr, il nous faut adopter une attitude proactive plutôt que de nous plaindre à longueur de temps. Nous nous devons de soutenir nos pairs et de coopérer avec nos collègues médecins. Bien sûr, il nous faut apprendre au public qui nous sommes et ce que nous représentons. Dans un article de Kitson des plus éloquents (1997), l'auteure avance que les infirmières ont besoin de nouvelles métaphores et images pour véhiculer l'essence de leur profession. Elle y suggère le slogan "Vous pourrez compter sur nous". Je n'ai aucun doute que les patients pourront compter sur nous, peu importe ce qui se passera. Je crois fermement que nous sommes en train de modifier la perception de l'infirmière par le grand public. Notre image change.

Cette année, le slogan de la Journée internationale des infirmières était "Les infirmières, toujours là pour vous". Lundi, nous avons examiné le thème de la Semaine nationale des soins infirmiers de 2001 retenu par l'AICC: Les infirmières Championnes de la santé. Votre présidente vous a incitées à "donner de la voix pour faire connaître vos accomplissements. À devenir la voix des soins infirmiers en oncologie au Canada".

Lundi, Janes et Robinson nous ont rappelé avec éloquence et créativité que les infirmières en cancérologie peuvent faire la différence, que le cancer est un invité importun au sein de la famille

et que les enfants doivent faire partie du tableau dès le départ. Il faut que nous intégrions les enfants dans l'œuvre collective que nous tissons sous forme de tapisserie des soins infirmiers en oncologie.

Les présentations des trois derniers jours indiquent clairement que nous faisons la différence dans le vécu des patients atteints de cancer au niveau des soins palliatifs, de la gestion des symptômes, de l'enseignement aux patients, de la dispensation de traitements comme la radiothérapie, les greffes de moelle osseuse, l'oncologie pédiatrique et même l'élaboration de programmes innovateurs en matière de soins d'urgence et communautaires. Tout au long de la conférence, on a pu remarquer la force de la recherche infirmière, un autre fil voyant de notre œuvre. Il nous revient de montrer que nous faisons la différence, que nous dispensons des soins de qualité, à un coût abordable.

Nous constituons "Le fil continu des soins aux patients". Nous allons quitter cette conférence pour retourner dans nos milieux respectifs, avec je l'espère, une nouvelle dose d'engagement, d'énergie et d'enthousiasme pour continuer la tapisserie que nous avons démarrée. Les contributions individuelles à cette conférence forment une œuvre d'art collective qui participe à la création actuelle et future de la tapisserie des soins infirmiers en oncologie.

En tant qu'infirmières et citoyennes du monde, nous créons le futur par ce que nous faisons ou ne faisons pas aujourd'hui. C'est avec fierté que nous admirons la tapisserie des soins infirmiers créée par celles qui nous ont précédées. Que chacune d'entre nous, au moment de tisser les points qui forment notre partie de la tapisserie, se souvienne que les infirmières qui nous suivent poseront à leur tour leurs yeux sur notre œuvre. Espérons qu'elles n'y verront aucune imperfection, aussi minuscule soit-elle. La tapisserie que nous tissons pour le monde du 21^e siècle a pour seules astreintes nos valeurs, nos ressources, notre vision et notre imagination. ✨

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Evaluation of a breast self-examination (BSE) program in a breast diagnostic clinic

by Margaret I. Fitch, Judith McPhail, and Edmee Franssen

Abstract

The purpose of this study was to evaluate the short-term effectiveness of a breast self-examination (BSE) teaching program on women's knowledge about BSE, proficiency in performing BSE, and motivation to perform BSE. The program was developed for delivery by nurses in a breast diagnostic clinic, a clinic designed to meet the need for expeditious management of breast disease, current information about breast cancer risk, surveillance, and counselling. A convenience sample of 68 women attending the clinic in a regional cancer centre participated in a pre- and five month post-teaching program evaluation. The Toronto Breast Self Examination Instrument was used as the evaluation tool. There were statistically significant changes following the teaching program in the areas of knowledge about the correct technique for performing BSE, proficiency performing BSE, and confidence about finding changes when performing BSE. No significant changes were observed in motivation to practise BSE, although group scores did improve following the education. Participants found the video presentation and the review of BSE information pamphlets by the nurse to be the most helpful components of the BSE teaching program.

Breast cancer continues to be the most frequently diagnosed cancer for Canadian women (NCIC, 2000). With no prospects for primary prevention in the foreseeable future, there has been increased emphasis on early detection of the disease. Breast self-examination (BSE), as a technique for breast cancer detection, has the appeal of being self-generated, non-intrusive, inexpensive, and avoiding radiation risk. BSE is simple to do and can be performed in approximately 10 minutes (Mayer & Solomon, 1992).

An estimated 70% of breast cancers are discovered by women themselves. However, these tumours are usually found by accident, not as part of a BSE program (Hall, 1992). BSE may enhance detection of interval cancers that occur between routine screening examinations (Baines & To, 1990). A woman who knowledgeably performs BSE can facilitate diagnosis by drawing her physician's attention to newly developed abnormalities. In addition, she will avoid the false reassurance that may follow negative results from mammography or clinical breast examination (Harvey, Miller, Baines, & Corey, 1998).

Despite uncertainty regarding the effectiveness of BSE in influencing outcomes, particularly mortality reduction (Baines, 1997; Gastrin et al., 1994; Harvey, Miller, Baines, & Corey, 1997; Newcomb et al., 1991; Thomas et al., 1997), education about BSE is

offered as part of a total breast health package, which also includes mammography and clinical breast examination, in our breast diagnostic clinic. The educational program was developed for delivery by nurses in an ambulatory practice and includes multiple teaching strategies. This article describes the evaluation of this BSE educational intervention.

Before one can determine the effectiveness of BSE for early detection in breast cancer, it is imperative to determine that BSE teaching programs are effective in producing expected performance and compliance (Alcoe, Gilbey, McDermot, & Wallace, 1994). Additionally, educational interventions need to be evaluated within the context or environment in which they are delivered (Brooten & Naylor, 1995; Hailey, Lalor, Byrne, & Starling, 1992). Factors in the situation may have an influence on the effectiveness of an educational program. Our interest was to evaluate the effectiveness of our BSE teaching program as it was delivered in a busy ambulatory setting.

Background

The Canadian National Breast Screening Study (NBSS) suggests that most women who enter screening programs upgrade their BSE skills if subjected to brief periods of repeated instruction (Baines & To, 1990). Two extensive reviews of relevant literature on BSE education concluded that training can improve compliance, confidence, and proficiency (Clarke & Savage, 1999; Nettles-Carlson & Smith, 1988).

ABRÉGÉ: ÉVALUATION D'UN PROGRAMME D'AUTO-EXAMEN DES SEINS DANS UNE CLINIQUE DIAGNOSTIQUE DU SEIN

Cette étude avait pour but d'évaluer l'efficacité à court terme d'un programme d'enseignement de l'auto-examen des seins (AES) relativement aux connaissances des femmes concernant l'AES, leur compétence d'utilisation de cet examen et leur motivation à l'employer. Le programme a été conçu pour être dispensé par les infirmières d'une clinique diagnostique du sein ayant pour mandat de répondre aux besoins relatifs à la gestion diligente du cancer du sein, à la diffusion d'information à jour sur les risques, à la surveillance et aux consultations. L'échantillon de convenance comprenait 68 femmes qui participaient au programme offert par la clinique située dans un centre régional de cancérologie; l'évaluation du programme d'enseignement se divisait en deux volets: le premier préalable à la tenue du programme et le second cinq mois après sa fin. L'instrument d'évaluation retenu était l'Instrument d'auto-examen des seins de Toronto. Des changements statistiquement significatifs marquaient la tenue du programme d'enseignement dans les domaines suivants: connaissances relatives à la technique appropriée d'exécution de l'AES, compétence d'utilisation de l'AES et degré de confiance dans le repérage de changements lors de l'exécution de l'AES. On n'a remarqué aucun changement significatif au niveau de la motivation à exécuter l'AES, bien que les résultats du groupe se soient améliorés à la suite de la dispensation de l'enseignement. Selon les participantes, la présentation vidéo et l'analyse de la documentation sur l'AES effectuée par l'infirmière constituaient les composantes les plus utiles de ce programme d'enseignement de l'AES.

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Although teaching BSE does improve practice, it is not yet clear which aspects of teaching protocols contribute the most to proficient practice, or whether group or individual approaches are more effective (Clarke & Savage, 1999). In general, the use of multiple strategies has emerged (Agars & McMurray, 1993). For example, the addition of a formal instructional class to physician encouragement increased accuracy in BSE assessment (Strickland et al., 1997), and Champion (1989) found that women whose knowledge and technique were reinforced by a nurse or physician practised BSE more regularly. In 1995, Champion reported that a teaching protocol consisting of information, BSE demonstration, and return demonstration significantly increased logged proficiency, observed proficiency, and nodule detection one year post intervention. In another study (Katic, Lang, & Budak, 1996), a method which included theory, group discussion, practical training on a silicon breast model, individual practice of BSE, and additional individual assessment of acquired skill was effective in increasing the number of women practising BSE. The use of an interactive multimedia strategy resulted in greater learning about breast health for younger women in a general practice setting (Street, van Order, Bramson, & Manning, 1998).

Development of an education program must take into consideration the target population, potential barriers to performance of the desired behaviour, proven teaching modalities for the topic, and the environment or setting. The target population for the breast diagnostic clinic is women under the age of 50 who are perceived to be at increased risk for breast cancer. Although the issue of breast cancer in younger women has received more attention in recent years, little is known about the surveillance patterns and psychological characteristics of younger women who are at increased risk for the disease (Lerman, Kash, & Stefanek, 1994). This age group is important for BSE teaching because of the large number of Canadian women born between 1946 and 1966 (baby boomers) and the fact that breast screening guidelines for mammography in this country target women over the age of 50.

Certain characteristics have been identified in persons who do practise BSE. These characteristics include receiving personal instruction in BSE technique, as well as individual recommendations to perform BSE; having a sense of confidence in performing BSE; holding a belief in the personal value of performing the procedure; and perceiving a lack of barriers in carrying out BSE (Leight & Leslie, 1998). Variables that have shown a consistent relationship with increased BSE include knowledge of BSE technique, belief in BSE as a detection procedure, and self-confidence in performing BSE (Hailey, et al., 1992). Conversely, potential barriers to regular performance of BSE include a lack of confidence in the ability to perform BSE, extensive reliance on physicians for screening, difficulty remembering to perform the behaviour, and anxiety about breast cancer and BSE (Nettles-Carlson & Smith, 1988). Although the literature presents conflicting perspectives, it is believed that anxiety, especially in younger women or those with higher levels of education, is thought to motivate attendance at a breast cancer screening facility (Gram & Slenker, 1992). The content of one's BSE teaching program needs to consider these various issues.

The breast diagnostic clinic (BDC) of the Toronto-Sunnybrook Regional Cancer Centre (T-SRCC) was established to meet the need for expert, expeditious management of breast disease including the provision of current information on breast cancer risk, counselling, and surveillance. The BDC is held one evening each week in the regional cancer centre. The clinic attracts a population of women under the age of 50 who are or perceive themselves to be at increased risk of breast cancer and who refer themselves to the clinic. An interdisciplinary team including family physicians, surgeons, nurses, and a psychologist provides care. Patient education is a priority. The nurse-physician interaction is collaborative, with physicians frequently setting the

stage for BSE training and the nurse providing the in-depth instruction.

Given the pace of the breast diagnostic clinic, the relatively short appointment times, the environment of a cancer setting, the age of the women attending the clinic, and the perceived anxiety of those in attendance, the BSE teaching program was designed to be delivered by the nurse within the context of the clinic appointment. The educational challenge was to provide the necessary information and opportunity for skill development in a short time period when the learner may be worried about a cancer diagnosis. The BSE program was designed to influence knowledge about breast cancer risk and BSE as a method of detection, as well as improving skill and confidence in performing BSE.

The BSE teaching program consisted of four components: 1) BSE information pamphlets which the nurse reviewed with the patient, 2) a video that addressed the benefits of BSE and clearly demonstrated the proper technique, 3) demonstration of BSE by the nurse using the patient as the model, and 4) return demonstration by the patient on herself with the nurse observing. A breast model was used for the second demonstration if the patient expressed difficulty in feeling lumps. The teaching took about 20 minutes to complete.

Purpose

The purpose of this study was to evaluate the short-term effectiveness of an educational intervention on desired learning outcomes: a) knowledge about BSE, b) proficiency in performing BSE, and c) motivation to practise BSE. The BSE teaching program incorporated a combination of teaching strategies shown to be effective in other settings. However, it was important to determine if the program being delivered was effective in the context of the breast diagnostic clinic.

Methods

Procedures

The evaluation used a pre-post test approach. All new patients registered for assessment in the breast diagnostic clinic (BDC) during a six-month interval were approached regarding participation in the study. The only ineligibility criteria were the inability to speak or read English and having received BSE instruction within the previous month. Those who were eligible but declined participation in the evaluation still received the educational program. Those who agreed to participate in the evaluation completed two instruments, the Toronto Breast Self-Examination Instrument (TBSEI) (Ferris, Shamian, & Tudiver, 1991) and the State-Trait Anxiety Inventory (STAI) (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983), prior to undergoing the BSE teaching program. Immediately following completion of the program, participants completed the TBSEI knowledge subscale. Five months later, women completed the entire TBSEI again and rated which part of the BSE teaching program they had found most helpful. Ethical approval for this evaluation study was given by the Sunnybrook Health Science Centre Research Ethics Committee.

Sample

Of the 145 new patients registered for assessment in the BDC during the six-month evaluation period, 68 were ineligible or declined to participate in the evaluation study. Women were ineligible for the following reasons: not being able to speak English (n=8); recently taught BSE (n=9); and other (n=6), such as pregnancy and cognitive impairment. The reasons women gave for not wanting to participate included not enough time to stay at the clinics and participate (n=31), scheduled for tests or surgery (n=9), and feeling too upset (n=5).

Seventy-seven women gave written, informed consent to participate in the study. However, nine of them (12%) did not complete the TBSEI at the five-month interval, so the final sample size was 68. These nine women represented a cross-section of breast cancer risk categories, anxiety scores, and reported frequency of BSE.

Evaluation tools

Basic demographic information, including age, marital status, education level, source of referral, and risk status for breast cancer, was obtained from the patient's chart. The outcomes of interest, including knowledge about BSE, proficiency in performing BSE, and motivation to perform BSE, were assessed using the TBSEI (Ferris et al., 1991). This instrument provides a standardized self-administered measurement with established reliability estimates and validity properties (Ferris et al.). The TBSEI's three scales include proficiency (frequency and proficiency of BSE practice), knowledge (knowledge of breast cancer and of BSE), and motivation (perceived susceptibility and reasons for BSE practice). The 60 items are precoded and the tool usually requires 15 minutes to complete. Although it is theoretically ideal to assess proficiency of practice through observation, the paper-and-pencil approach was used in this evaluation to reduce the need for office visits and highly trained personnel. Additionally, the TBSEI allows for the assessment of various steps concerning appropriate BSE practice (i.e., correct technique, appropriate frequency).

Subscale scores for knowledge about BSE are calculated using a five-point scale with each of the 20 items and the following options: strongly disagree (scored as a -2), disagree (-1), neither agree nor disagree (0), agree (+1), and strongly agree (+2). The range in potential scores for this subscale is -40 to +40.

Scores for proficiency included answers to items about frequency of BSE, proficiency of practice and self-confidence. Scores are calculated using five-point options with the exception of one question that has a seven-point option. The TBSEI scoring system was originally designed to identify habitual performers. It was adapted in this study to reflect the ideal situation (i.e., BSE performed 10 to 12

times per year). Thus high proficiency scores reflect monthly and systematic BSE practice. The range in potential proficiency scores is 0 to 11.

Subscale scores for motivation are calculated using a five-point scale with each of the items and the following options: strongly disagree, disagree, neither disagree nor agree, agree, strongly agree. A "neither agree nor disagree" was scored a "0" in accordance with the scoring guidelines of the TBSEI (Ferris et al., 1991). The range of potential scores for this subscale is -32 to +32.

The STAI (Spielberger et al., 1983) has established reliability and validity properties and measures anxiety both as a situational response and as a personality trait. The instrument has 40 items with precoded answers and takes about 10 minutes to complete. Scores are generated for both state and trait anxiety. Within this study, anxiety was measured as a baseline variable because of its possible influence on BSE and breast screening behaviours.

Participants' perspectives on the helpfulness of the various components of the BSE teaching program were gathered at five months. A list of the components of the BSE program was provided and the women were asked to indicate which ones were most helpful to them.

Analysis

Data were entered into an ORACLE database and analyzed using SAS UNIX (statistical software package SAS Institute Inc). Item frequency counts and total scores were calculated for the TBSEI and STAI at baseline (time one) and the TBSEI at five months (time three). Frequency counts and total scores were calculated for the knowledge subscale of the TBSEI for time two (immediately after completion of the BSE teaching program). Frequency counts were also calculated for demographic items. Given there are no absolute values for high and low anxiety published for the STAI, we used the median as the cut-off point. For both baseline trait and state anxiety scores, participants were divided into two groups, those with anxiety scores above the median and those with scores below the median. Baseline knowledge, proficiency, and motivation scores were compared for these two groups using t-tests. Participants were also grouped on the basis of their risk for breast cancer (i.e., those at or slightly above general population risk for breast cancer and those with moderate/high risk for breast cancer). Baseline anxiety scores for these risk groups were compared using t-tests.

Table One: Selected sample demographics
(n=68)

| Characteristic | Frequency |
|------------------------------|-----------|
| Age in years | |
| 20-29 | 14 |
| 30-39 | 24 |
| 40-49 | 24 |
| 50-59 | 4 |
| 60-69 | 2 |
| Marital status | |
| Single | 11 |
| Married/common law | 53 |
| Divorced/other | 4 |
| Highest education completed | |
| Primary school | 1 |
| High school | 10 |
| Some college/Some university | 12 |
| College | 16 |
| University | 29 |

Taking into consideration independence of the subjects and distribution of the variables, appropriate statistical tests (analysis of variance, t-tests, McNemar) were used to determine differences in knowledge, proficiency and motivation following the teaching program. Differences in knowledge were compared for two intervals: 1) pre-teaching vs immediately after teaching, and 2) pre-teaching vs five months following teaching. Differences in motivation and proficiency were compared for pre-teaching and five months post-teaching. To adjust for multiple testing, p values were considered significant at 0.001.

Results

Sample characteristics

Sixty-eight women completed the evaluation measures at all data collection points. The demographic characteristics for this sample are presented in Table One. The women ranged in age from 20 to 69 years of age, with those in the middle years (30 to 49 years) comprising 35% of the sample. Eighty-seven per cent of the women were Caucasian and 75% were married. Eighty-four per cent completed some post-secondary school and 43% completed university. Although their occupations varied, most women worked in business (24%) or health care (19%), or were homemakers (22%).

The majority (78%) of the women were referred to the breast diagnostic clinic by physicians. Many had had previous exposure to BSE through brochures (59%), physicians (49%), breast cancer education program (11%), relatives (10%), nurses (7%), and television (6%). Only 4% had not had previous exposure to BSE instruction at some point in time.

Forty-seven per cent were categorized as "at moderate/high risk" for breast cancer and 53% as "at or slightly above general population risk." None of the women had ever been treated for breast cancer, although 29% had received treatment for benign breast disease. A majority (78%) of the women were still having menstrual periods. Eighty-one per cent of the women had been pregnant and their mean age at first live birth was 27 years.

Anxiety

At baseline, the mean trait anxiety score was 40.2 (standard deviation 8.6), with a range of 28 to 62. The mean state anxiety score was 38.2 (standard deviation 10.4), with a range of 21 to 64. The median anxiety score for the participants was 37.5.

The student t-test revealed no significant differences in anxiety scores (n=68, trait, p= 0.2515; state, p= 0.3104) between the group of women with "at or slightly above general population risk for breast cancer" and those in the group of "moderate/high risk for breast cancer." There were also no significant differences concerning anxiety scores in relation to education level (trait, p= 0.446; state p= 0.464) or age (trait, p= 0.212; state, p= 0.947). No significant differences were observed for knowledge, proficiency, or motivation at baseline in relation to anxiety (see Table Two).

Knowledge

Participants' knowledge scores at baseline (before BSE teaching program) ranged from three to 39 with an average score of 18.5 (standard deviation = 0.4). Immediately after the BSE teaching program, participants' knowledge scores ranged from four to 36 with an average of 24.1 (standard deviation = 8.6). Five months after the BSE teaching program, participants' knowledge scores ranged from 2 to 40 with an average of 22.5 (standard deviation = 8.3).

Based on results from repeated measures of analysis of variance, there was a statistically significant time effect (p< 0.0001) on the participants' knowledge scores between the three different measurement points. The mean change of score in participants' correct responses to the knowledge items was 5.5 (p<0.004) from the time before teaching to immediately after the BSE program, whereas the mean change was 4.1 (p< 0.0001) from the time before the teaching to five months after the BSE program. Seventy-eight percent of the women had a higher score immediately after the BSE teaching program than at baseline and 87% of these maintained a higher score five months after the BSE teaching.

Of particular clinical importance, at baseline none of the participants provided correct answers for the five questions regarding the steps of the BSE procedure. At five months, 13 women (19.1%) provided correct answers to all five questions. The difference in the proportion of women who provided the correct answer was statistically significant (McNemar's test statistic=13, p<0.0001).

Selected knowledge questions reflected modest change following the teaching program. At baseline, 96% of the participants reported learning the BSE technique previously. However, only 68% of the women responded correctly to the item regarding the best time of the month to perform BSE before a woman reaches menopause. At five months, 93% of the women responded correctly to this item (McNemar's test statistic=7.12, p<0.01). In response to the item, "the

best time to perform BSE after a woman reaches menopause is at the same time each month," 60% agreed with this statement at baseline and 93% agreed with it five months later (McNemar's test statistic, p<0.0001). Knowledge about the incidence of breast cancer did not improve. Ten per cent of the participants at baseline agreed that the incidence of breast cancer increases with age, while 7% agreed with the statement at five months.

Proficiency

At baseline, participants' proficiency scores ranged from 0 to 8, with an average of 2.5 (standard deviation = 2.1). Five months following the intervention, proficiency scores ranged from 0 to 11, with an

Table Two: Exploring the influence of anxiety on proficiency, motivation, and knowledge scores at baseline (n=68)

| | Proficiency scores (mean/sd) | Motivation scores (mean/sd) | Knowledge scores (mean/sd) |
|--|---------------------------------|--------------------------------|-------------------------------|
| Groups based on trait anxiety scores | | | |
| Below 39 (n=36) | 2.6 (2.2) | 14.6 (4.8) | 20.7 (7.6) |
| 39 and above (n=32) | 2.3 (2.0) | 12.1 (6.1) | 16.1 (8.7) |
| Groups based on state anxiety scores | | | |
| Below 37.5 (n=34) | 2.6 (2.1) | 14.2 (4.9) | 19.6 (7.1) |
| 37.5 and above (n=34) | 2.3 (2.1) | 12.6 (6.2) | 17.5 (9.5) |
| <i>No significant differences observed between means</i> | | | |

average of 5.9 (standard deviation = 3.1) The mean score for changes in proficiency scores was 3.4 (standard deviation = 2.8). A significant increase in the mean proficiency scores was observed from baseline to five months following the BSE teaching program using a paired t-test ($p < 0.0001$).

Of clinical interest, participants were asked how often they performed BSE during the past 12 months. At baseline, 12% reported a frequency of performance that was the ideal ("10-12 times") and five months later, 18% reported a performance of "10-12 times." At baseline, 43% reported a performance that was poor ("not at all" or "one-three times") and five months later, only 26% reported a performance that was poor. Although a general trend toward increased frequency of performance was observed five months following the BSE teaching program, the difference was not statistically significant.

Confidence levels in performing BSE increased following the BSE teaching program. At baseline, 12% of the participants reported feeling "very confident" or "confident" they could find changes when they performed BSE. At five months, 40% of the participants reported feeling "very confident" or "confident." The difference in the proportion of women feeling confident is significant (McNemar's test statistic=16.2, $p < 0.005$).

Motivation

Baseline motivation scores ranged from -2 to 25, with an average of 13.43 (standard deviation = 5.6). Five months after the educational intervention, scores ranged from -2 to 22, with an average of 14.0 (standard deviation = 5.6). From baseline to five months following the BSE teaching program, the mean score for changes in motivation was 0.6 (standard deviation = 5.0). Using a paired t-test, no significant difference in motivation scores was observed between baseline and five months following the BSE teaching ($p = 0.340$).

Helpfulness of the BSE program

Some participants provided an indication of the components of the BSE teaching program they found helpful. The components rated as most helpful included the video ($n=25$), review of information pamphlets by the nurse ($n=17$), demonstration by the nurse ($n=9$), and return demonstration by the patient ($n=5$). Participants also noted that knowledge of BSE, proficiency in performing BSE, as well as knowing what to do when changes in the breast were observed, were aspects that required continual reinforcement.

Discussion

This study was undertaken to evaluate the effectiveness of a teaching program about BSE on women's knowledge, proficiency, and motivation. The program was designed for implementation in a breast diagnostic clinic. It was delivered in the context of a clinic appointment by an oncology nurse.

The main limitations of this evaluation were the self-selected nature of the clinic population and the lack of a control group. Women seeking breast cancer screening already constitute a more motivated group than those who choose not to attend. Women who come to the diagnostic clinic, and hence those in this sample, may have a higher incidence of breast problems, a stronger family history, and be more knowledgeable of the risk involved when breast cancer is not detected early than the general population (Morrison, 1996). Another limitation lies in the self-reporting of frequency and proficiency of BSE. These may have been inflated by a self-report bias. Finally, the educational level of participants is higher than the general population, although the sample reflects the registrants at the breast diagnostic clinic.

Of the participants, 91% were under the age of 50 and 47% were categorized as moderate/high risk for breast cancer. This illustrates the enhanced awareness of breast cancer in young, well-educated women. Thirty per cent of diagnosed breast cancer cases occur before the age of 50 years (NCIC, 2000). For women under 50 who are not eligible for organized screening programs, early detection appears to require an approach encouraging regular BSE, thus emphasizing the need for effective instruction programs with information relevant to the targeted population.

Major findings concur with prior research concerning effectiveness of an educational intervention on women's knowledge, proficiency, and motivation for BSE practice. Our results indicate improvement in self-reported proficiency scores and provide additional support that the teaching of BSE will produce a significant increase in the reported frequency of practice and level of confidence over an extended period of time (Alcoe et al., 1994). The importance of confidence in performing BSE is consistent with self-efficacy theory which suggests that confidence in one's skills will predict adoption and persistence of any health behaviour (Bandura, 1977).

Participants' overall knowledge of breast cancer and BSE showed positive changes with improvement immediately after the educational intervention, and a minimal decrease five months following the intervention. However, key messages were lost, such as the breast cancer risk factor of age. This observation raises questions about the learning environment and whether younger women at increased risk for breast cancer may be selective about what knowledge is needed or retained. As well, health information may seem filled with inconsistencies and make it difficult for individuals to decide what has relevance for them. Alonzo (1993) suggests that health educators may well face a significantly desensitized population. Clear information is needed to increase breast cancer knowledge.

The emphasis of the education program was on BSE proficiency. The increase in the proportion of women who answered five questions about the BSE procedure correctly on the proficiency scale was significant. A significant positive relationship between knowledge and observed BSE quality has been reported elsewhere (Alagna and Reddy, 1984).

Participants' motivation scores improved only slightly after intervention. This may be influenced by the nature of the sample. Only 18% of our participants reported BSE practice of 10-12 times a year at five months. Other authors have reported rates of 46% in a sample of registered nurses (Budden, 1998) and 82% in a sample of women in a general practice setting (Katic et al., 1996). Although it is difficult to compare these populations, the variations in performance along with the links to motivation and beliefs about BSE are worthy of future investigation.

For the participants in this evaluation, there was no difference in anxiety between the categories of risk for breast cancer. This finding differs from results of a study with younger women (under age 50) at increased risk for breast cancer who reported serious psychological morbidity (Lerman et al., 1994). Perhaps women's cancer anxiety levels were ameliorated by mere attendance at a surveillance clinic where their concerns around risk can be addressed.

Based on our findings, we plan to maintain the BSE educational intervention in our breast diagnostic clinic with its emphasis on experiential learning and self-care management. Teaching BSE will continue to be an integral component of nursing practice because participants favoured the involvement by a nurse in the explanation of BSE and guided experience. The video presentation will also be utilized together with the other program components. Although participants found the BSE video presentation helpful, as also noted by DeMuth (1989), the video still requires one-on-one interaction with the physician or nurse.

Conclusion

These evaluation results support the effectiveness of the BSE teaching program on participants' proficiency, including self-confidence and knowledge about the BSE procedure, over a five-month period. However, the duration of follow-up was limited. We do not know the effectiveness of the intervention during the maintenance phase (i.e., one to two years after intervention). Key messages about breast cancer risk were not improved. The review by the nurse and the video presentation were the most favoured parts of the intervention.

Resources for this type of instruction required special training of nurses, 15 to 20 minutes of a registered nurse's time, a breast model,

a VCR/video that is available in most clinics and physicians' offices, and pamphlets that were donated by the Cancer Society or pharmaceutical companies. For a small capital investment and operating costs for BSE education, there are benefits for both women's health and the health care system. ♦

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A comprehensive review of selected cancer websites

By J. Lynn Stapleton

Abstract

With increasing availability of information on the Internet, it makes sense for health care professionals to use this resource to expand the range of resources available to both themselves and to clients. This paper was designed to provide health care professionals with a starting point from which to gather further website oncology resources. An established template for evaluating websites is described and criteria regarding the accuracy of information, site design, and navigation are examined. While the initial phase of this paper evaluated numerous sites, only the top five as noted by the author are presented here.

Individuals have various needs that arise during the different stages of their cancer. DeGrasse and Hugo (1996) cite the Ontario Cancer Treatment and Research Foundation definition for the Supportive Care Framework which addresses the following needs: physical, emotional, informational, psychosocial, spiritual, and practical. Each of these areas is important in determining how the individual copes with his or her diagnosis. Searching for information is a commonly used coping mechanism once an individual is diagnosed with cancer. Furthermore, the patient controls the amount and technical degree of information that he or she seeks (DeGrasse & Hugo).

Increasing numbers of patients and families are using the Internet as a means of gathering information and support. Professionals are then often faced with questions about information obtained this way. With the explosion of resources available via the Internet, including the number of website links to cancer information, it makes sense for health care professionals to utilize this information to expand their knowledge base.

It can be quite overwhelming for health care professionals and patients to access information about a particular type of cancer, treatments, clinical trials, research data, or statistics. A general scan of different search engines such as Altavista, Yahoo, and Excite! can turn up millions of hits. Altavista logs more than 3.5 million sites reporting

information on cancer. Yahoo reports 92 categories and 2,385 sites for cancer. Excite! logs more than 372,000 sites on cancer. There are many different focus areas for cancer information.

Grahn and Swenson (1998) state that "the Internet is one of the newest, fastest-growing, and most visible examples of changes in technology, communication, and marketing" (p.231). There are many aspects of the Internet from which the health care professional/patient/families can look for information, such as websites, newsgroups, e-mail lists, and cancer-related chat rooms. This paper, however, will specifically look at websites for cancer.

This paper evaluates five cancer websites chosen by the author for their comprehensiveness and wide range of reliable, relevant information. The websites were evaluated using two main categories: types of information provided and categorical review of web design. For patients and health care workers searching for information, there are many sites that look at general and specific information about cancer. These sites provide information about defining cancer, as well as how to treat specific cancers using chemotherapy, radiation, and/or surgery. Some sites break down the cancers by body site/system. Other sites examine some of the complementary and alternative interventions that have been demonstrated to work in conjunction with standard cancer treatments. Several of the sites provide definitions of specific terms used, particularly if the site is aimed at the general public.

Joel Goldwein and Ivor Benjamin, editors-in-chief of OncoLink (a service of the University of Pennsylvania Cancer Center), provide a valuable template to evaluate cancer websites. OncoLink uses the following categories for the evaluation criteria: 1) accuracy of information, 2) availability of editorial staff, 3) qualifications of editorial staff, 4) freshness of content, 5) disclosure of conflicts of interests, 6) price of information, 7) confidentiality, 8) reputation, 9) look and feel, and 10) navigation and searching. The editors define each aspect of what they expect to find in each website for cancer. This OncoLink resource was the template used for reviewing the following five websites.

American Cancer Society (ACS) (<http://www.cancer.org>)

The American Cancer Society is a national voluntary organization. This website examines the various education, resources, actions, research, advocacy, and care which the ACS provides. Information is available in English and Spanish.

1. The information posted here is properly referenced with peer-reviewed material (journals, texts, periodicals).
2. E-mail contact is made available through this website. The site asks for e-mail, name, address, phone number, and type of information requested. It also states that due to the volume of e-mail requests or comments, responses may take up to 10 days. However, a 1-800 number is provided if immediate response is required.
3. The editorial staff collect information for review of education, resource, and research materials for this website. Positions include a) a medical editor who is a board-certified physician in oncology medicine with a minimum of five years clinical experience, computer literate, and comfortable with the Internet; b) a project manager for web community who has a bachelor's degree in humanities, marketing, or management, and has a background in health care or non-profit groups; c) a web developer who has a bachelor's degree or equivalent in education and two years experience in developing, managing, and marketing of Internet sites; and d) a web master who has a bachelor's degree in computer science plus three years experience with networked computers, one year in a web master role, or equivalent combination in education and experience.
4. The American Cancer Society is updated daily with new information as it becomes available. The index page includes the ACS News Today which has daily news and information.
5. No disclosure of conflicts noted.
6. The information provided on this site is free to access. There is a link to free brochures and information provided by the American Cancer Society. The ACS also has a bookstore where specific books or journals on cancer can be bought, either by phone (credit card orders only), cheque or money order (by mail), or on-line via a secured site (credit card orders only) via a partnership with <http://www.amazon.com/>
7. If buying products from the bookstore, a secured website is provided so that credit card purchases are encrypted for security. As well, donations to the ACS via the web are possible through a secured website. E-mail requests to the ACS are examined in confidence, as specific patient information may be requested before further advice or suggestions are given.

8. Resources are provided by researchers and clinicians in oncology who work toward improving the provision of cancer information from the American Cancer Society.

9. This website is well laid out and requested information is quite easy to locate. Toolbars allow you to locate the information quickly. There are few graphics on the main site, so downloading of information is quick.

10. If the user is unable to immediately locate specific information, an internal search engine is available to find that material. The site also provides a comprehensive resources list so the user can check out other resources, both internal to the site as well as external links.

Canadian Cancer Society (CCS) (<http://www.cancer.ca/>)

This site provides information about the different aspects of cancer, from signs and symptoms to treatment and resources, as well as cancer statistics for Canada. It also looks at Canadian research in oncology, as well as services provided by the Canadian Cancer Society. The CCS is a voluntary agency. Information is provided in English and French.

1. Information provided falls in accordance with the American Cancer Society website.

2. Questions or concerns regarding the site can be directed to Darla McKay at webadmin@cancer.ca

3. Darla McKay is a web administrator for the Canadian Cancer Society and the National Cancer Institute of Canada.

4. There are no dates of when information is posted or updated.

5. No disclosure of conflicts noted, though there are many sponsors of the Canadian Cancer Society as it is a voluntary agency which relies on donations, both private and

corporate. This website lists the sponsors of the CCS.

6. Information provided on this site is free of charge to the user.

7. The Canadian Cancer Society notes on the website that users should submit private information to their Cancer Information Service by phone [1-888-939-3333], Monday to Friday, 9am-6pm, while general information requests can be sent via e-mail to info@cis.cancer.ca. Donations can be made at local offices of the CCS, rather than on-line donations.

8. The Canadian Cancer Society has been in existence since 1937 and is associated with the Canadian Medical Association's National Study Committee on Cancer Research in Canada.

9. This site does not have very many graphics, thus making it quick to download material. The look is clean and free of cluttered information. The information is laid out in a well designed format. The on-line pamphlets are clear and well designed. The data are up-to-date in accordance with current data available.

10. This site is quite easy to navigate. Download time is quick. Links connect to the appropriate pages. There is no search engine available on the site, however, if you require further information the site does provide links to the American Cancer Society - <http://www.cancer.org> and the National Cancer Institute (USA) - <http://www.nci.nih.gov>.

CancerGuide: Steve Dunn's Cancer Information Page (<http://www.cancerguide.org>)

Steve Dunn's guide to cancer information is designed to help people find both information on cancer and resources. He

offers a guide on how to research cancer information, as well as providing some links to medical sources of data.

1. Though the information is well researched, Mr. Dunn is not a physician or medical expert. He has spent a lot of time doing research for his own cancer experience and has chosen to share this information with others.

2. Steve Dunn - steve.dunn@cancerguide.org

3. Mr. Dunn is a cancer survivor who teaches information on cancer clinical trials.

4. Content on each page of this site is updated as new materials become available. For the most accurate information, he refers the user to other sources, such as CancerNet, as well as links to oncology books.

5. No disclosure of conflicts noted.

6. The information on this site is free to the user.

7. Mr. Dunn provides a link where people can include their stories about their own experiences with cancer. This area does require information about the user, however, it is voluntary as the user does not have to include his or her own experiences. There are a few guidelines that Mr. Dunn sets out for including stories, which are available via a link in his site (Dunn, 1999).

8. Mr. Dunn specifies that he is not a physician and requests that any individual questioning their health/illness consult their physician, though the material may assist the user in the types of questions to be asked.

9. The site is text only with the exception of a few diagrams. The information is well presented and in a format that can easily be understood by the user. The information is quick to download and a site map assists the user to find information.

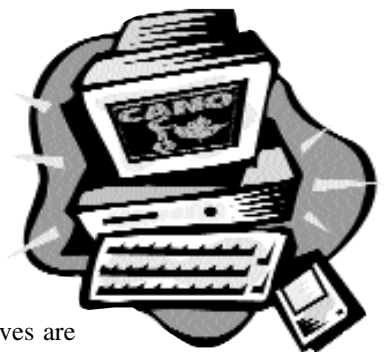
10. The links within and from this site work easily. There is no search engine on this site.

CANO is on the web!!!

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

- go to the Canadian Oncology Society's (COS) website, found at www.cos.ca
- when the COS home page appears, click on the number 5 in lower portion of left-hand side of screen; this will take you to the next screen
- on the left-hand side of the new screen, click on "Affiliated Societies"
- members of COS will appear. Scroll down until you find CANO
- click on CANO's name
- you will arrive at CANO's home page where the philosophy, mission, and goals and objectives are easily viewed
- CANO's home page also allows you to obtain a membership form and/or obtain access to CANO's secure web pages
- if you want to obtain a membership form or learn more about membership benefits, click on "Membership Application and Benefits"
- to access CANO's secure web pages, click on "CANO members"
- follow directions to obtain your password
- once you have your password, your journey through CANO's web pages will begin!!

Have fun learning more about CANO! Don't forget - your comments are important to us. Please let us know how we are doing by e-mailing the web pages working group at r3kchapman@health.nb.ca.



CancerNet (A service of the National Cancer Institute [NCI]) (<http://cancer.net.nci.nih.gov>)

This site provides a comprehensive gathering of cancer information in order to provide resources to patients, friends and families, and health care providers. Research data, statistics, available treatments, clinical trials, signs and symptoms, specific cancers information, as well as supports and resources are highlighted.

1. The information on this site is compiled by the National Cancer Institute's office of cancer information, communication, and education (OCICE). Most of the information comes from the NCI's comprehensive database, physician data query (PDQ), whose editorial board is comprised of physicians specializing in cancer.
2. There are several contacts available. The director of the office of cancer information, communication, and education can be reached at director@icic.nci.nih.gov. The CancerNet staff can be reached at cancer.net.staff@mail.nih.gov.
3. Board-certified physicians and specialists in the many types of oncology and related specialties make up the editorial staff.
4. Content is routinely updated on a monthly basis, though new updates are added when available to provide the most up-to-date information.
5. No disclosure of conflicts noted.
6. Information provided free for use by the user, however, there is a licensing agreement

Useful resources

- AltaVista search engine
<http://dir.altavista.com/>
- Amazon On-Line
<http://www.amazon.com>
- American Cancer Society
<http://www.cancer.org>
- Canadian Cancer Society
<http://www.cancer.ca>
- CancerGuide: Steve Dunn's
Cancer Information Page
<http://www.cancerguide.org/>
- CancerNet (a service of the
National Cancer Institute)
<http://cancer.net.nci.nih.gov>
- Excite! search engine
<http://search.excite.com/>
- National Cancer Institute (USA)
<http://www.nci.nih.gov>
- OncoLink (a service of the
University of Pennsylvania)
<http://oncolink.upenn.edu>
- Yahoo search engine
<http://ca.search.yahoo.com/>

to universities, commercial, and non-profit organizations.

7. CancerNet respects the privacy of its users. Data about the number of users, domain name or IP address, date and time page was accessed, type of browser used, operating system, and whether or not CancerNet was linked from another site are collected for statistical reference. E-mail addresses are logged only so that responses can be made to queries. No data are collected that can identify an individual user.
8. As mentioned, this site is managed by the National Cancer Institute, the largest of 17 specializations of the National Institutes of Health. It provides accurate, current information to patients, the public, and health care providers.
9. This website is very well designed and laid out. The topics are broken down by category: types of cancer, treatment options, clinical trials, genetics, causes, risk factors and prevention, testing for cancer, coping with cancer, support resources, cancer literature, and PDQ. There are not many graphics, so the page is quick to download.
10. The Intranet and Internet links connect quickly and are easily located. If the user is unable to directly find something on the site, the site provides a "frequently asked questions" (FAQ) area for new users and a search engine for Intranet data.

OncoLink - University of Pennsylvania Cancer Center (<http://oncolink.upenn.edu/>)

OncoLink provides a detailed site of hypertext links to information concerning all aspects of cancer in order to improve education, research, and knowledge about cancer to patients, family, caregivers, and health care professionals.

1. The available information has been properly referenced with authors and dates. The information comes from reliable sources within the health care profession.
2. Both postal and e-mail addresses are provided, as well as phone/fax numbers. E-mail: editors@oncolink.upenn.edu
3. Ivor Benjamin, MD, is a gynecologic oncologist at the University of Pennsylvania Cancer Center (UPCC) (ibenjamin@mail.obgyn.upenn.edu). Joel W. Goldwein, MD, is a radiation oncologist at UPCC (goldwein@cr.t.upenn.edu). James Metz, MD, is a

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- De Grasse, C.E., & Hugo, K. (1996). Supportive care needs of women undergoing breast diagnostics and their families: A focus for nursing interventions. **Canadian Oncology Nursing Journal**, 6(2), 185-190.
- Dunn, S. (1999). **Story guidelines**. Available online: http://www.cancer.guide.org/story_guidelines.html
- Grahn, J., & Swenson, D. (1998). Recasting education and research processes for mutual student/faculty benefits. **Journal of Education for Business**, 73(4), 230-234.

radiation oncologist and Maggie Hampshire, RN, BSN, OCN, is an oncology clinical nurse, both at UPCC.

4. Site is updated daily with new information, tips, resources, research, and clinical trial information. Included at the top of the page is a "What's New" section.
5. No disclosure of conflicts noted.
6. Information provided here is free to the user.
7. A privacy statement is available on the main site and outlines the security policies regarding any personal information divulged through contact with site editors and information requests.
8. OncoLink is designed by and based from the University of Pennsylvania Cancer Center.
9. The information is neatly presented, clearly understandable, and has interesting and relevant graphics. The site is well organized and easy to use. The information can be understood by patients, family members, and health care professionals.
10. Easy to find your way around the website through links provided. Links are functioning properly. The site search engine is powered by Altavista.

These cancer websites are recommended by the author of this paper as being the top five web resources for cancer information for health care professionals, patients, and family members. They provide the most comprehensive collection of information regarding the varied aspects of cancer, clinical treatments, resources, supports, and research data. A pamphlet (available in English and French) to complement this paper is currently being used as a patient cancer website resource tool for the Region 3 Hospital Corporation in New Brunswick. 🌟

About the author

At the time this article was written, Lynn Stapleton was a third year nursing student at the University of New Brunswick's Fredericton campus.

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President's Message

CANO and the challenge to change

As I write this, my last president's message to you, I look back over the last two years as your president with a mixture of pride, anxiety, and considerable exhaustion! Like all of you in your workplaces and personal lives, time marches on ever so quickly. Most of us scramble to keep up to the challenges of "giving it our best" while struggling to maintain balance in our lives.

It has been a turbulent time of change in the organization and in health care in general. Many nurses find it difficult to give time to support professional organizations like ours, when just keeping up to their normal work and family life seems more than one can handle. Thus, it has been a privilege for me to work with so many of you over my last four years on the CANO board and to see our many major accomplishments, especially in strategic planning and the development of our new standards.

My experience at the national level over the last four years has been as director on the board representing British Columbia, on the CANO pain initiative, founding member of CONEP, on the national certification committee, and then as president for the last two years. I have had many discussions with other similar professional groups and, not surprisingly, we are all facing difficulties that relate to the challenge of being a non-profit, volunteer, national organization at a time when the health care system and its workers are said to be in "crisis."

When difficult times face us, sometimes we imagine that someone is at fault or we need to find someone to blame. It will be important for us to remember that this is not productive and, as your president, I would like to make it clear that we face a set of unique circumstances that "challenge us to change!"

Our strategic planning project resulted in a revised "Mission, Vision, and Values" statement and the development of six strategic objectives for our organization over the next few years. The strategic directions are in six areas: membership recruitment, fiscal stability, leadership profile, patient advocacy, organizational infrastructure, and standards.

continued on page 150...

President's Message

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A small strategic planning group attended a weekend retreat in Calgary at the end of May. The goal of the workshop was to produce a blueprint for change which could be discussed by the board and then voted on by the membership as

a whole at the annual general meeting. Many CANO board, committee, and initiative members have recognized for some time that our present organization structure is no longer meeting our needs. We will be working hard to consider the options available to us and be ready to present an action plan at the AGM.

I hope to see you in Quebec at our first conference in that province! It promises to be a wonderful time together, a time to share our wisdom and caring with and for each other and to plan for the future of oncology nursing in Canada.

Carolyn Tayler, CANO President

Message de la Présidente

L'ACIO et le défi du changement

À l'occasion de la rédaction de ce qui constitue mon dernier Message de la présidente aux lectrices de la Revue, c'est avec un mélange de fierté et d'angoisse et avec une fatigue prononcée que je jette un regard sur mes deux années à ce poste! Comme pour vous toutes, que ce soit du point de vue professionnel ou personnel, le temps passe si vite. La plupart d'entre nous doivent produire de grands efforts pour faire de notre mieux au travail tout en essayant de maintenir un certain équilibre de vie.

Notre association a vécu une période de changements tumultueux qui caractérise également les soins de santé dans leur ensemble. Les infirmières sont nombreuses à avoir du mal à soutenir leurs organismes professionnels tels que le nôtre en leur donnant de leur temps, alors que le seul fait de maintenir la cadence régulière de la vie au travail et de la vie de famille semble dépasser nos moyens. Ce fut donc pour moi un privilège de pouvoir travailler avec tant d'entre vous au cours de mes quatre dernières années au Conseil national de l'ACIO et de voir se réaliser tant d'accomplissements d'envergure, notamment la planification stratégique et l'élaboration de nos nouvelles normes.

Mon expérience nationale au cours de ces quatre années a pris les formes suivantes: membre du conseil d'administration pour la Colombie-Britannique, membre de l'initiative de l'ACIO sur la douleur, membre fondateur du Projet canadien de formation en oncologie (CONEP), membre du Comité national de la certification, présidente de l'association durant les deux dernières. Je me suis entretenue à maintes reprises avec des représentantes de groupes professionnels semblables au nôtre, et nous n'avons pas été surprises de constater que nous devons toutes faire face aux difficultés associées à la gestion d'organismes nationaux sans but lucratif et bénévoles alors que le système des soins de santé et ses travailleurs traversent une "crise".

Lorsque nous vivons des moments difficiles, nous nous disons parfois que c'est de la faute de quelqu'un et qu'il faut en faire endosser la responsabilité aux personnes jugées responsables. Il importe de ne pas oublier que cette attitude n'est pas du tout productive et j'aimerais vous expliquer, en tant que présidente, que nous avons devant nous un ensemble de circonstances uniques en leur genre qui nous "obligent à changer"!

Notre initiative de planification stratégique nous a permis d'actualiser notre énoncé de "Mission, Vision et Valeurs" et de doter notre organisme de six objectifs stratégiques pour les prochaines années. Les

orientations stratégiques concernent les six domaines ci-dessous: recrutement de membres, stabilité financière, profil du leadership, défense des intérêts des patients, infrastructure organisationnelle et normes.

À la fin mai, un petit groupe de planification stratégique a participé à une séance de réflexion tenue à Calgary tout au long d'une fin de semaine. Elle avait pour but de produire un plan détaillé des changements à venir qui pourrait être débattu par le Conseil national et être soumis à l'approbation des membres dans le cadre de l'Assemblée générale annuelle (AGA). Un nombre important de membres du Conseil national de l'ACIO, de ses comités et initiatives soulignent depuis quelque temps que notre structure organisationnelle actuelle ne répond plus à nos besoins. Nous ferons tous les efforts possibles pour étudier les options qui s'offrent à nous et préparer un plan d'action pour l'AGA.

J'espère que j'aurai le plaisir de vous voir à la conférence de Québec, la première à se dérouler dans la belle province. Elle s'annonce prometteuse et ce sera pour nous l'occasion de partager notre sagesse, de nous écouter et de nous appuyer mutuellement et de façonner l'avenir des soins infirmiers canadiens.

Carolyn Tayler,
Présidente, ACIO

Maurice Legault Fellowship Award - 2001-2002

Are you considering full or part-time studies in *clinical* oncology nursing? If so, you may be pleased to know that the **Canadian Cancer Society** offers financial support to some of Canada's best oncology graduate nursing students.

Your training must last between three and 12 months and part-time studies are acceptable! Two fellowships are offered each year at a value of \$18,870 plus \$1,000 for tuition and \$1,000 for travel and/or professional meeting costs!

Terms and conditions of the award and application forms may be found 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 the Maurice Legault Award please contact Heather Logan at (416) 934-5658 in advance of the **November 15, 2001 deadline for applications!**

13th Annual CANO Conference

The art of communication: Sharing our stories

CANO 2001

– September 23-26, 2001

**Hotel Loews Le Concorde,
Quebec City**

The CANO 2001 planning committee has been working hard in the last few months to organize a stimulating conference from both a scientific and a human perspective. We look forward to welcoming many of you at this conference entitled “The art of communication: Sharing our stories.”

Communication is at the heart of nursing practice, not only with cancer patients but with our colleagues and health professionals from other disciplines. Take advantage of this educational opportunity to re-energize and learn and share with other nurses from all over Canada, with the beautiful colours of Quebec’s early fall as a backdrop.

The conference’s keynote will be bilingual. Simultaneous translation services will be provided for all plenary conferences, educational breakfasts and lunches and CANO’s annual general meeting. A wide choice of workshops emphasizing nurses’ expertise in all areas of oncology and all regions of our country will be offered.

The preliminary program was mailed out in June. We trust that you received your registration and have already sent it back. If not, there is still time, but you should hurry! If you want to take advantage of the \$163 hotel room price at the Loews Le Concorde, the site of the conference, you must reserve your room before September 1 by calling 1-800-463-5256. After this deadline, the regular price will be in effect.

Don’t miss our lamb roast at the sugar shack on the Tuesday night, where you’ll see old friends and colleagues and develop your professional network in a festive country atmosphere. We look forward to welcoming you!

Registration fees:

By August 15, 2001

- Early bird registration

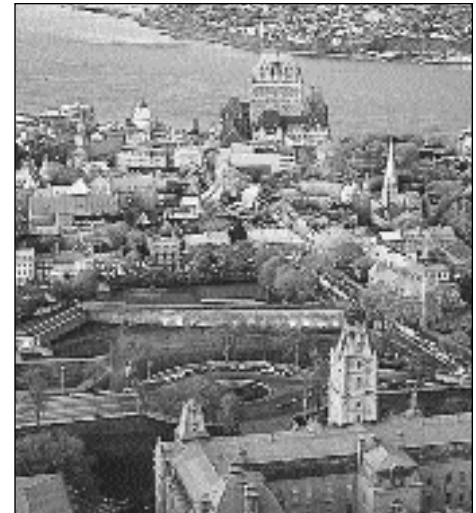
| | |
|-----------------|----------|
| CANO member | \$290.00 |
| Non-CANO member | \$375.00 |
| Student | \$160.00 |

After August 15, 2001

| | |
|-----------------|----------|
| CANO member | \$350.00 |
| Non-CANO member | \$440.00 |
| Student | \$160.00 |

On-site registration

| | |
|--------------------------|--------------|
| CANO member | \$385.00 |
| Non-CANO member | \$485.00 |
| Student | \$160.00 |
| Pre-conference workshops | \$50.00 each |



Canadian Association of Nurses in Oncology

Agenda for CANO annual general meeting

Tuesday, September 25, 2001 - 0730-1030

- 1.0 Call to order – Carolyn Tayler
- 2.0 Adoption of agenda
- 3.0 Approval of AGM minutes – October 17, 2000
- 4.0 Business arising
 - 4.1 Reports
 - 4.1.1 Finance
 - 4.1.2 Research
 - 4.1.3 ISNCC
 - 4.1.4 NCIC
 - 4.1.5 Web pages
 - 4.1.6 Canadian Strategy for Cancer Control
 - 4.2 Management office
 - 4.3 CONJ
 - 4.4 Special initiatives
 - 4.4.1 Fatigue
 - 4.4.2 SIGS
 - 4.4.3 Canadian Oncology Nursing Education Project
 - 4.4.4 Pain
 - 4.4.5 Strategic Plan
- 5.0 New Business
 - 5.1 Bylaws
 - 5.2 Budget – 2001-2002
 - 5.3 Appointment of auditors
 - 5.4 Nominations
- 6.0 Information sharing
 - 6.1 New award by Eli Lilly Inc.
- 7.0 Next meeting
- 8.0 Adjournment



Treizième conférence annuelle de l'ACIO

L'art de communiquer : se raconter pour de découvrir

Conférence de l'ACIO 2001

– du 23 au 26 septembre, 2001

Hotel Loews Le Concorde, Québec

Depuis plusieurs mois, le comité organisateur de la conférence de l'ACIO 2001 travaille fort pour préparer un congrès enrichissant sur le plan scientifique et humain. C'est donc avec un vif plaisir que nous vous attendons en grand nombre pour participer à cette conférence sur le thème de « L'art de communiquer : se raconter pour se découvrir ».

La communication est au cœur de notre pratique infirmière, tant avec les personnes atteintes de cancer qu'avec nos collègues et les autres professionnels de la santé. Venez profiter de ces journées éducatives pour vous ressourcer, apprendre et partager avec vos collègues de tout le Canada, dans les belles couleurs du début de l'automne à Québec.

Ce congrès se tiendra sous le signe du bilinguisme. Toutes les conférences plénières seront traduites simultanément, ainsi que les déjeuners et dîners éducatifs et l'assemblée générale de l'ACIO. Un grand choix d'ateliers vous est offert ce qui mettra en évidence l'expertise des infirmières dans tous les domaines de l'oncologie et toutes les régions du pays.

Le programme préliminaire vous a été envoyé en juin. Nous espérons que vous l'avez bien reçu et que vous nous avez déjà fait parvenir votre inscription. Sinon, il est toujours temps de le faire mais hâtez-vous ! Si vous voulez profiter du prix de 163 \$ pour les chambres à l'hôtel Loews Le Concorde où se tient le congrès, vous devez faire votre réservation **avant le 1^{er} septembre** en appelant au 1-800-463-5256. Après cette date, c'est le prix régulier qui s'appliquera.

Ne manquez pas notre méchoui à la cabane à sucre le mardi soir qui vous permettra de revoir des collègues et d'enrichir, dans une atmosphère de fête à la campagne, votre réseau de connaissances. Nous avons hâte de vous accueillir !

Hâtez-vous de vous inscrire !

Frais d'inscription

Lettre postée d'ici le 15 août

| | |
|-------------------|-----------|
| Membres de l'ACIO | 290.00 \$ |
| Non membres | 375.00 \$ |
| Étudiantes | 160.00 \$ |

Après le 15 août

| | |
|-------------------|-----------|
| Membres de l'ACIO | 350.00 \$ |
| Non membres | 440.00 \$ |
| Étudiantes | 160.00 \$ |

Inscription sur place

| | |
|-----------------------|--------------------|
| Membres de l'ACIO | 385.00 \$ |
| Non membres | 485.00 \$ |
| Étudiantes | 160.00 \$ |
| Atelier pré-congrès : | 50.00 \$ chacun |



L'association canadienne des infirmières en oncologie

Ordre du jour de l'assemblée annuelle de l'ACIO

Mardi, le 25 septembre 2001 - 07h30 - 10h30

- 1.0 Ouverture de l'assemblée – Carolyn Tayler
- 2.0 Adoption de l'ordre du jour
- 3.0 Adoption du procès verbal de l'assemblée générale annuelle – 17 octobre 2000
- 4.0 Revue de la dernière réunion
 - 4.1 Rapports
 - 4.1.1 Finances
 - 4.1.2 Recherche
 - 4.1.3 ISNCC
 - 4.1.4 INCC
 - 4.1.5 Pages Web
 - 4.1.6 Stratégie canadienne de lutte contre le cancer
 - 4.2 Gestion
 - 4.3 RCSIO
 - 4.4 Projets spéciaux
 - 4.4.1 Fatigue
 - 4.4.2 Groupes d'intérêt spéciaux
 - 4.4.3 Projet de formation infirmière en oncologie (CONEP)
 - 4.4.4 Douleur
 - 4.4.5 Plan stratégique
- 5.0 Affaires nouvelles
 - 5.1 Règlements
 - 5.2 Budget – 2001-2002
 - 5.3 Nomination des vérificateurs
 - 5.4 Présentation des nouveaux membres du comité de direction
- 6.0 Mise en commun de l'information
 - 6.1 Nouveau prix - Eli Lilly Inc.
- 7.0 Prochaine réunion
- 8.0 Levée de la séance



CANO/Pharmacia Awards of Excellence

Editor's note: As previously reported in CONJ, two of the award winners were initially unable to respond before the deadline. I am delighted to include their contributions now and I apologize for not being able to publish their words along with the other award winners.

Lorna Butler (Research, 1996) is "privileged" to work in a shared position where she supports the conduct of clinical nursing research at Dalhousie University School of Nursing and the Queen Elizabeth II Health Sciences



Centre. Seventy per cent of her time is spent at the university and 30% in the clinical setting. She also has an affiliate scientist position within the Faculty of Medicine, Department of Urology, and is in the second year of a tenure track associate professor position at Dalhousie.

Lorna noted, "Responding to the question of how I contribute to oncology nursing is both challenging and thought-provoking. In many ways, one's contribution is measured by the perception of others and the impact of being and learning with other oncology nurses that we experience. My career has been focused on the development of new knowledge that supports and recognizes the significance of experiential learning as one aspect of knowing what we do and why we do it in clinical practice. My work has been guided by the voices of oncology nurses and my role has been to provide a forum for that voice to be heard that has traditionally been silent in the clinical research arena. The contribution is not

mine, but it is the culmination of many nurses who have worked to advance oncology nursing locally, provincially, and nationally in our research. The true contribution I may make to oncology nursing will most likely be unknown to me personally, but will be in the hearts and minds of those with whom I share a belief in what it means to be an oncology nurse. As a new professor at the university, I have been humbled by the brilliance of graduate nurses I have worked with in the classroom. If I could wish for what my contribution could be, it would be to instill the confidence and belief that these nurses have the support they need to put that knowledge to use, to take those risks they aspire towards, with success, and to know that nursing is proud of who they are and what they are doing for the delivery of care."

When Lorna won her award, the honour was announced within her hospital and in her provincial newspaper. She accepted the award at the 1996 conference "on behalf of the oncology nurses and other members of our research teams." She hangs the plaque in her office as a visible recognition of what she and her colleagues had accomplished. Lorna also takes all opportunities to proudly explain its significance. She believes that the teams felt rewarded and motivated to continue to make research come alive in a huge bureaucratic, institutional system that was experiencing nursing research for the first time. This award is a visible sign to the health care community that she and her colleagues are making a difference, study by study and team by team.

Lorna was encouraged to continue her work as a result of the award, "...winning an award that is judged by one's peers is perhaps the highest acknowledgement of what is valued and credible by those with whom we

strive to improve our profession. The award was received early in my research career and in the beginning work of creating an environment that would allow nurses to conduct independent research in a teaching hospital. Many days, this was a "tough battle" and the togetherness of many individuals, most often staff nurses, helped to make the struggle worthwhile. Professionally, the award was timely and demonstrated to the hospital that nurses had an academic contribution to make which involved a research mandate.

Personally, the award meant that taking a risk is what research is about. Research not only pushes for change, but is the instrument of change. It was not acceptable to maintain the status quo or sit on the fence when cancer care was rapidly evolving. Being on the edge of discovery and sharing the excitement of ground-breaking work for nurses was my job. This was what I had studied to do. The award sent me a message that being on the edge, regardless of how hard that might be, had not been lost on those around me. My risks were shared and I was not really alone. This was the incentive to launch the next study!"

In her final comments, Lorna wrote, "The awards of excellence mark a point in time in careers that span a lifetime. As a new researcher, but a seasoned oncology nurse, it was part of a new beginning. The challenge was, and continues to be, maintaining that standard. Living up to the expectations of the criteria to receive such an award is not accomplished in isolation. Building a future that reflects this award is a shared responsibility among all oncology nurses in Nova Scotia, Canada, and around the world."

Carreen O'Connor (Education, 1996) works at the Northeastern Ontario Regional Cancer Centre as an educator within the prevention and education program. She sees her contribution to oncology nursing as arising from a centre-wide perspective where she is a resource for nurses and managers. Her role is not profession-specific, but rather she meets the needs of programs. Carreen notes that, "learning is recognizing the value of needs assessment and intervening with education programming that assists staff to meet performance expectations."

Carreen was delighted to have her work recognized by her peers because it, "is a tremendous validation of your everyday work. It provides an incentive to continue when your intrinsic motivation is faltering. The award on the wall is a constant reminder of that peer validation."

In her conclusion, Carreen expressed gratitude to her colleagues for the nomination and the support she received and continues to receive.

A message for members of CANO about the International Society of Nurses in Cancer Care events/proposals

By Ann Hilton, RN, PhD

The next conference for the International Society of Nurses in Cancer Care (ISNCC) will be held in August 2002 in London, England. The call for abstracts is out and the deadline for receipt of abstracts is August 31, 2001. You can find out more about the call by going to the ISNCC website which is: www.isncc.org. You can download the call for abstracts from the website and there are several options for you to send an abstract in. Last August the conference was held in Oslo, Norway and a great time was had by all.

The ISNCC also has a small research grant program. You can find out information about that on the website too. The deadline for receipt of proposals will be October 15 this year. I hope some of you consider submitting a proposal.

For your information, CANO is a member organization of ISNCC. Unlike CANO where members are individuals, the members of ISNCC are organizations. I am CANO's representative and a board member of ISNCC. As such, I am one of the two North American representatives on the board. Canada is quite fortunate because we currently have two people on the board, myself and Marg Fitch. Marg is the president-elect of ISNCC.

So - hope you think about coming to London in 2002, whether you present a paper or not. If you have any questions, please feel free to call me at (604) 822-7498 or e-mail me hilton@nursing.ubc.ca.

ACIO - Pharmacia prix d'excellence

Note de la Rédactrice: Comme nous l'avons signalé dans le numéro précédent de la Revue, deux des lauréates n'avaient pu envoyer leur réponse dans les délais impartis. J'ai le plaisir de publier leurs contributions dans le présent numéro en m'excusant de n'avoir pu les inclure avec les autres.

Lorna Butler (Recherche, 1996) se sent "privilégiée" d'appuyer la recherche infirmière clinique en partageant son temps entre l'École des sciences infirmières de l'Université



Dalhousie et le Queen Elizabeth II Health Sciences Centre. Elle passe ainsi 70 % de son temps à l'université et 30 % dans l'établissement de soins cliniques. Elle occupe également un poste de scientifique associée au département d'urologie, Faculté de médecine, et en est à la deuxième année d'un poste menant à la permanence à titre de professeure adjointe à l'Université Dalhousie.

Mme Butler s'est exprimée ainsi: "Répondre à la question sur ma contribution aux soins infirmiers en oncologie est un défi qui favorise la réflexion. De bien des façons, notre contribution se mesure à l'aune de la perception d'autrui et à l'impact qu'exercent sur nous la présence d'autres infirmières et l'apprentissage effectué ensemble. Ma carrière s'est intéressée au développement de nouvelles connaissances qui reconnaissent et appuient l'importance de l'apprentissage expérientiel car elles nous aident, entre autres choses, à savoir ce que nous faisons en pratique clinique et pourquoi nous le faisons. Mes travaux ont été guidés par la voix des infirmières en oncologie; mon rôle a été de fournir la tribune permettant à cette voix de se faire entendre dans le domaine de la recherche clinique, un domaine où elle était restée silencieuse jusque-là. Cette contribution ne m'appartient pas personnellement, elle représente plutôt l'aboutissement des efforts de nombreuses infirmières qui ont fait progresser la recherche infirmière en oncologie à l'échelle locale, provinciale et nationale. Je ne connaîtrais probablement jamais mon apport véritable aux soins infirmiers en oncologie, mais il se reflétera

dans le cœur et l'esprit de celles qui partagent l'idée que je me fais de notre spécialité. Ma récente nomination à l'université m'a amenée à admirer, en toute humilité, l'intelligence des infirmières diplômées avec lesquelles j'ai travaillé en classe. Si je pouvais choisir la nature de ma contribution, je voudrais que ce soit que ces infirmières sachent et pensent qu'elles ont le soutien nécessaire pour appliquer leurs connaissances, prendre les risques qui les mèneront aux buts qu'elles souhaitent atteindre et que la profession infirmière est fière de ce qu'elles sont et de ce qu'elles font au niveau de la dispensation des soins."

Lorsque Mme Butler s'est vu décerner le prix, son établissement et le quotidien de sa province l'ont annoncé publiquement. Et c'est "au nom des infirmières en oncologie et des autres membres de nos équipes de recherche" qu'elle a accepté le prix au cours de la conférence de 1996. Elle a accroché la plaque dans son bureau, un rappel visible de ce qu'elle avait accompli avec ses collègues. Mme Butler profite aussi de toutes les occasions pour expliquer fièrement l'importance du prix. Elle estime que les équipes se sentaient ainsi récompensées et motivées à poursuivre le développement du secteur de la recherche dans un gigantesque système bureaucratique et institutionnel, appelé à accueillir la recherche infirmière pour la toute première fois de son existence. Ce prix est un message bien visible adressé au monde des soins de santé: elle et ses collègues font la différence, une étude et une équipe à la fois.

Le prix a incité Mme Butler à poursuivre ses travaux; "...un tel prix dont l'évaluation est faite par nos pairs est peut-être la plus haute reconnaissance de la valeur et de la crédibilité de nos activités professionnelles aux yeux des personnes qui, comme nous, s'efforcent d'améliorer notre profession. J'ai reçu ce prix dans les premiers temps de ma carrière en recherche et lors de la mise en place d'un environnement favorable à la conduite, par des infirmières, de recherches indépendantes au sein d'un hôpital d'enseignement. Ce fut, à maintes reprises, une lutte acharnée, mais l'esprit de corps de nombreuses personnes, le plus souvent des infirmières de chevet, m'a aidée à apprécier l'utilité de cette lutte. Dans une perspective professionnelle, le prix est tombé à point et il montrait bien à l'hôpital que les infirmières avaient une contribution universitaire à faire en matière de recherche.

D'un point de vue personnel, le prix signifiait que la prise de risque est

l'essence même de la recherche. Celle-ci promeut le changement et en est aussi le vecteur. Il était inacceptable d'accepter le statu quo et de ménager la chèvre et le chou alors que les soins en oncologie connaissaient une évolution rapide. Mon travail consistait à me positionner aux premières lignes des découvertes et à faire connaître les travaux innovateurs pour les infirmières. C'était ce à quoi mes études m'avaient préparée. Le prix véhiculait un message, que d'être aux avant-postes pouvait s'avérer difficile mais que mes efforts avaient été remarqués par mon entourage. Je n'étais pas vraiment seule et la prise de risque était partagée. C'était tout l'encouragement qu'il me fallait pour démarrer la prochaine étude!"

Les commentaires de Lorna Butler se terminaient ainsi: "Les prix d'excellence ponctuent des trajectoires professionnelles s'échelonnant sur toute une vie. Pour moi, chercheuse débutante mais infirmière en oncologie chevronnée, le prix marquait le début d'un nouveau chapitre. Le défi consistait, et consiste encore, à respecter cette norme. Être à la hauteur des critères gouvernant l'attribution d'un tel prix ne se fait pas en restant isolée. La construction d'un avenir à l'image de ce prix est une responsabilité que se partagent toutes les infirmières en oncologie de la Nouvelle-Écosse, du Canada et du monde entier."

Carreen O'Connor (Éducation, 1996) occupe un poste d'éducatrice au sein du Programme de prévention et d'éducation du Centre régional de cancérologie du Nord-Est de l'Ontario. Sa contribution aux soins infirmiers en oncologie, elle la voit dans la perspective d'ensemble qu'elle a de son centre où elle offre son soutien aux infirmières et aux gestionnaires. Son rôle n'est pas lié à notre profession, son mandat consistant plutôt à répondre aux besoins des programmes. Mme O'Connor ajoute que "l'apprentissage consiste à reconnaître la valeur de l'évaluation des besoins et d'intervenir en offrant des programmes de formation qui aident le personnel à répondre aux attentes en matière de rendement."

Mme O'Connor a été très heureuse de voir son travail reconnu par ses pairs parce que cela "représente une formidable validation des travaux quotidiens. Cela incite à continuer lorsque la motivation intrinsèque fait défaut. Le prix suspendu au mur me rappelle constamment la validation exprimée par mes pairs."

Dans sa conclusion, Carreen O'Connor remercie ses collègues de l'avoir nommée et du soutien qu'elles lui offrent depuis toujours.

Mark Your Calendar!

Prenez Date!

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

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

Publication dates Submission dates

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

Dates de publication

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

Dates de réception

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

- 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: Discovery through sharing of stories**
Thirteenth annual CANO conference. Loews Le Concorde Hotel, Quebec City, PQ.
Fee before August 15, 2001: member \$290.00, non-member \$375.00, student \$160.00.
Contact: CANO Office, 232-329 March Road, Box 11, Kanata, ON K2K 2E1, (613) 270-0711, fax (613) 599-7027, canoacio@igs.net
- October 12, 2001 **The Canadian Cancer Society Short-Term Clinical Oncology Training Program for Health Care Professionals in Canada.** Fall cycle.
Contact: Sarah Kettel, CCS (National), 10 Alcorn Avenue, Suite 200, Toronto, ON M4V 3B1. (416) 934-5673, fax (416) 961-4189, skettel@cancer.ca
- October 25-26, 2001 **ONIGA (Oncology Nurses Interest Group of Alberta) 2001 Conference.**
Greenwood Inn, Calgary, Alberta.
Contact: Meina Dubetz, (403) 670-8233, meinadub@cancerboard.ab.ca
- October 27, 2001 **From Seed to Soul.** London Oncology Nurses Interest Group Conference. Best Western Lamplighter Inn, London, ON. • Fee: \$60.00 CANO members; \$75.00 non-members; \$40.00 full-time students.
Contact: Fiona Wright, (519) 642-3733, wright2me@home.com
- November 9-11, 2001 **ONS Fall Institute,** St. Louis, Missouri. Contact: Pearl Moore, ONS, Pittsburgh, PA. Fax (412) 921-6565, member@ons.org
- November 14-16, 2001 **The Odyssey: IV Therapy in the New Millennium.** CINA 26th Annual Convention. International Plaza Hotel and Conference Centre, 655 Dixon Rd, Toronto, ON.
Contact: CINA, 18 Wynford Drive, Suite 516, North York, ON M3C 3S2, (416) 445-4516, fax (416) 445 4513, cinacsot@idirect.com or website <http://web.idirect.com/~csotcina>
- November 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
- November 16-17, 2001 **Pain and Symptom Management.** The Old Mill, Toronto, ON.
Contact: Continuing Education, Faculty of Medicine, University of Toronto, 150 College Street, Room 121, Toronto, ON M5S 3E2, (416) 978-2719, fax (416) 971-2200.
- January 25, 2002 **The Canadian Cancer Society Essay Prize for Oncology or Cancer Control (Nursing).**
N.B. Applicants must be in an undergraduate nursing program in Canada.
Contact: Monica Dixon, CCS (National), 10 Alcorn Avenue, Suite 200, Toronto, ON M4V 3B1. (416) 934-5673, fax (416) 961-4189, mdixon@cancer.ca
- Aug. 28 - Sept. 1, 2002 **Making a Difference.** Twelfth Annual International Conference on Cancer Nursing (ISNCC). London, UK. Contact: Emap Healthcare Events, Greater London House, Hampstead Road, London NW1 7EJ, UK, conference.healthcare@emap.com

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 nouveau-tés

Editor's Note: The following book review ran in the last issue of CONJ with the wrong publisher cited. The proper publisher is Butterworths Canada. CONJ apologizes for any inconvenience this may have caused.

Canadian nurses and the law (2nd ed.)

Authors J.J. Morris, M. Ferguson, and M.J. Dykeman. Published in 1999. Publisher: Butterworths Canada. Soft cover, 311 pages. ISBN # 0-433-41609. Cost: not available.

Reviewed by Brenda Peters-Watral

First edition author Morris has collaborated with co-authors Ferguson and Dykeman to produce this update of his 1991 book by the same title. This edition "represents an acknowledgement that neither the law, nor nursing practice, stays frozen in time...significant updating has been done to reflect the current state of the law," (p.iii). The authors note that the changing face of Canadian health care in the past decade has been accompanied by changes in legislation. Changes in health care delivery may also have legal implications for nurses, either currently or in the future. Although covering this content could make for a heavy read, the authors have presented the legal information that nurses need to know in an organized, practical format that is actually quite easy to read. As such, this is an important book for Canadian nurses, irrespective of their specialty.

This book provides a comprehensive reference for Canadian nurses on a broad range of topics with legal implications. An important strength of the book is that each of the 13 chapters covers a single topic, and can stand alone as a reference source on that particular issue. This is valuable for the nurse looking for a succinct source of information on a particular topic. While the entire text is interesting and valuable reading, those with limited time can concentrate on a chapter or two at a time without compromising the integrity of the overall message. The chapter topics include: Canadian health care facilities, Canadian health insurance, professional status of nurses, professional discipline and nursing, health records, mental health law, drugs, consent to treatment, nursing malpractice, inquests and inquiries, employment law, Canadian Charter of Rights and Freedoms, and current legal issues in Canadian health care.

The organization of the book also facilitates location of information on a particular topic. A complete list of all the legal cases cited in the text follows the table of contents. Each chapter

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.

begins with a text box summarizing the content of the chapter and ends with a brief synopsis of the current issues that relate to the topic of that chapter. This is followed by a listing of legislation relevant to the topic, both nationally and by province. The book ends with a selection of useful websites for Canadian nurses. The inclusion of many actual cases and trial transcripts throughout the book takes the place of the interesting and unusual photographs that are typically present in nursing literature, and serves a similar purpose of highlighting the significance of the commentary in the text.

The value of having a Canadian source on legal issues related to nursing and health care is perhaps too obvious to note. However, since this is an area where great differences exist between countries, the Canadian focus is another significant strength of the book.

The authors note in their preface that law and nursing practice are fluid, and this reality contributes to the most significant limitation of this and any other book on the same topic, that being the likelihood of quickly becoming outdated. This is particularly so in the current era of rapid change in health care. The reader should be aware of this and recognize that while this book would be a valuable addition to their library, even a mere year after its publication it cannot be considered a definitive source because of the fluidity of the topic. ♦

Brenda Peters-Watral, RN, MN, CON(C) is a clinical nurse specialist in the palliative care program at the Riverview Health Centre, Winnipeg, Manitoba.

Cancer nursing principles and practice (5th ed.)

Authors: C. Henke Yarbro, M. Hansen Frogge, M. Goodman, & S.L. Groenwald (Eds.). Published in 2000. Publisher: Jones and Bartlett Publishers: Sudbury, MA. Hard cover. 1911 pages. Cost: \$138.95 (US\$).

Reviewed by Lisa Bitonti, Margaret Cutrara, Victoria Harris, and Elley Pacey

Cancer nursing principles and practice (5th ed.) is intended to provide updated practice guidelines and references to all nurses practising in oncology. Readers should take particular note of the following:

- each chapter contains very detailed, comprehensive information about the chapter subject
- the authors include extensive websites and references to related topics for the nurse to pursue in more detail and to

update her/his knowledge base

- charts and tables are concise and convey information very clearly
- information is the most currently available for publication date (e.g. information on clinical trials, genetics)
- e-mail addresses for some of the key references are included, providing access to information beyond the text
- the authors address political and ethical issues that face oncology nurses and their patients
- the authors provide guidelines for effective communication so that the needs of the patients, nurse, and treatment centre are met
- decision tools are useful applications that nurses can bring to their practices
- the authors clearly explain the use of diagnostic procedures and related disease etiology
- colour photographs enhance the quality of the information provided
- the text is invaluable to any oncology nursing library.

While this text is excellent, individual reviewers had some suggestions for improvement:

- the large size of the book is awkward; two volumes would be easier to physically manage
- one volume could concentrate on the specific disease sites and the second volume could contain the remaining topics
- the book is costly, especially for individual nurses; if the individual sections were sold separately, this would be very helpful in alleviating some of the financial burden
- the addition of more photographs would be invaluable. For example, nurses play a major role in identifying the need for medical interventions in skin reactions from radiation therapy (especially in breast and head and neck cancers), or visual clinical signs of chemotherapy toxicities (e.g. hand-foot syndrome).

In summary, **Cancer nursing principles and practice (5th ed.)** is an essential nursing reference for the care and treatment of oncology patients. The book is comprehensive, detailed, and appropriate for the experienced oncology nurse. It may, however, intimidate the novice reader. The book is physically cumbersome, but the information is relevant as well as thought-provoking. ♦

Reviewed collectively by Lisa Bitonti, RN, BScN, Margaret Cutrara, RN, BScN, OCN, Victoria Harris, RN, CON(C), and Elley Pacey, RN, BA, CON(C). All are practising primary oncology nurses at the Toronto Sunnybrook Regional Cancer Centre, Toronto, ON. They represent many years of experience in various disciplines of oncology nursing.

for other treatments within his/her schedule.

No scheduling template can ever measure patient acuity. The template was designed as a means to schedule according to the nursing intensity of the treatment, not the nursing intensity of patient care. This brought to mind the number of miscellaneous nursing activities that we did within our chemotherapy unit that could not be quantified in measurable nurse intensity work minutes (see Table Four). At London Regional Cancer Centre (LRCC), we determined that the realistic and manageable workload for each chemotherapy nurse was approximately 360 minutes or 85% of the working day. This allowed for emergency treatments and unforeseen events.

The daily chemotherapy template takes into consideration nursing start and finish times, number of fixed chemotherapy nurses, number of specific categories needed, chair time needed by patient, number of chairs and beds available, flow of each oncology clinic, number of non-chemotherapy procedures needed, and breaks and lunches.

Implementation

One of the first tasks in initiating this process was to re-evaluate each medical oncology clinic booking system. Each physician/primary nurse team assessed their individual clinics and then designated certain clinic appointment slots as "chemotherapy follow-up" or "C-FLUP" slots. Designating these clinic appointments eliminated

competition for appropriate clinic appointment slots between patients "off" treatment and those "on" treatment. The need for a centralized booking system became apparent in coordinating appointments for all patients on active systemic treatment. The chemotherapy unit clerk undertook this task due to a good working knowledge of various chemotherapy protocols and an understanding of the workflow. In the new system, the chemotherapy unit clerk performs on-line booking of both clinic and chemotherapy appointments.

The interrelationships between departments was also factored into the new schedule. For example, pharmacy's workload and fixed staffing resources were considered. Twenty minutes is the minimum turnaround time required for pharmacy to prepare each order. Time studies showed that due to time restrictions in the haematology laboratory, processing of blood results took between 20 and 60 minutes. So, health information services identifies all laboratory requisitions for chemotherapy patients when chart prepping is done and all blood samples are marked in the laboratory for priority processing. As a result, all chemotherapy patients coming to the laboratory are identified and prioritized to expedite availability of blood results.

Keeping in mind the time requirements for the interrelated support services, we decided that all chemotherapy patients should be

given three appointment bookings that are coordinated by the chemotherapy unit clerk. Patients are booked for laboratory and x-ray (60-90 min. prior to clinic in order to process blood work and x-rays), clinic visit, and chemotherapy (60-90 min. following their clinic visit to allow for timely arrival of patient, processing of orders, and preparation of medications). Same-day chemotherapy treatments, unless previously booked, are restricted to emergent patients only or patients who live more than 100 km from the centre. If the chemotherapy unit cannot accommodate the patient for the same-day treatment, then the patient is prioritized for the next available appointment, usually within 24-48 hours.

Master chemotherapy booking lists showing appointment times in chronological order are printed in the chemotherapy unit, pharmacy, and the laboratory. Individual nurse workload assignment sheets are also generated showing appointment time, patient name and LRCC #, primary consultant, category of chemotherapy, regimen, and specific patient notes. A computer program was also developed to provide a daily report for actual nursing workload. This provides critical information for staffing needs: number of appointments booked in each category, number of patients booked, total sum of nursing intensity minutes, and projected total number of nurses required (see Table Five).

Impact

Patients: Three appointments instead of one may make the day appear longer for patients. However, waiting time between appointments is "free," so patients may leave as they please. Although patients can no longer walk into chemotherapy without an appointment, when they arrive for a scheduled appointment, the drugs, nurse, and space are available.

Laboratory: Sufficient time is now allowed for blood work processing during the patient's clinic /chemotherapy appointments. Laboratory staff know which patients are designated for chemotherapy and so can prioritize them. Patients are assigned appointment times, but several patients have similar times so patients can arrive from up to

six different clinics at a time. Clinic staff make fewer phone calls to the laboratory requesting blood work for patients receiving chemotherapy.

Physicians: Clinic reorganization was required to designate specific "chemotherapy only" slots, although no clinics had to move to different times or days. Physicians adjusted to a new way of booking patients, including emergent

Table Four: Miscellaneous nursing activities (not included in nurse intensity work minutes)

- Phone calls/VON + patient + primary nurse + referrals (home care, social work, dietary)
- New patient teaching
- Patient problems requiring physician intervention and new orders
- Difficult IV starts
- Checking blood products
- Patient personal needs (e.g. vomiting, incontinence, assistance with ambulation)
- Assessments on direct patients
- Assessing central lines and problem-solving
- Reactions to blood products, antiemetics, or cytotoxic agents
- Unscheduled patient visits

Table Five: Actual and planned nursing workload for chemotherapy resource

| Clinic Date | A | B | C | D | E | F | G | H | I | Number of patients | Nurse time (minutes) | Nurses needed |
|----------------------------------|----|----|----|----|----|----|-----|-----|-----|--------------------|----------------------|---------------|
| Direct nursing time (in minutes) | 20 | 30 | 45 | 60 | 75 | 90 | 120 | 150 | 240 | | | |
| April 14, 1998 | 4 | 22 | 4 | 23 | 3 | 0 | 0 | 2 | 0 | 58 | 2825 | 7.85 |

patients, and they accept that some unscheduled patients may not receive chemotherapy that day.

Nursing: There has been a major shift in approach from "first come, first served" to assigned patients, breaks, and space. The workload is more evenly distributed, nurses are under less stress, and the work environment is safer than before. Nurses now have time to assess patients and to prepare for the delivery of treatments. Re-education of clinic and chemotherapy nurses in explaining waiting time and next-day treatment to patients has been successful.

Pharmacy: An accurate chemotherapy appointment schedule allows for prioritization and a more organized work flow. Drugs are prepared in a timely fashion in the 20-minute minimum turnaround time. However, patients who arrive late for their scheduled appointment may delay the preparation of drugs for patients who arrive on time.

Continuous quality improvement

Periodic time studies have been undertaken to assess the effectiveness of our new scheduling system. The times monitored are: arrival at the clinic, time blood is drawn in the laboratory, time blood results are faxed to the clinic, clinic appointment time, arrival in chemotherapy, time orders arrived in pharmacy, chemotherapy appointment time, time the drugs are received, and actual time patient's treatment was initiated. Each time study has shown the need for each component (i.e. patient, nurse, pharmacy, laboratory, etc.) to adhere to the time requirements structured in the scheduling system.

Conclusion

In retrospect, the time involved in reviewing other systems, current needs, patient treatments and procedures, and

nursing requirements was greatly outweighed by the benefits achieved in implementing a chemotherapy scheduling system. Schedules are only as good and functional as the commitment by all key players. For this schedule to work, there must be staff collaboration along with patient and staff education. As treatment types and drugs continue to change, the scheduling system must be flexible to adjustments and modifications. This system has improved the working environment in the chemotherapy unit at LRCC. More importantly, however, it has encouraged a greater awareness of the patient's needs and requirements. ❖

Marcia Langhorn, RN, CON(C), is a chemotherapy resource nurse at the London Regional Cancer Centre, London, Ontario. Connie Morrison, RN, CON(C), is a primary and chemotherapy nurse at the London Regional Cancer Centre.

Editor's note: Mr. Gerritse wrote this article in January 2001. By the time I received it, however, he had sadly died of cancer. His widow, Barbara, sent a reply to my letter to Mr. Gerritse and I would like to share her words with you because they touched my heart.

Food for Thought

Alf Gerritse passed away of cancer on February 3, 2001. He was born in Holland August 15, 1930. He studied briefly in France hoping to become a doctor. He later became a "conscientious objector" to avoid being sent to war, which was abhorrent to him. He immigrated to Canada in 1952, where he married and had two daughters. He loved nature, gardening and Canada.

He held many types of jobs, but I think more than anything he wanted to write, taking extensive home study courses and attending workshops. He was a healthy, robust, affable man, respected by many for his intelligent, pragmatic approach to all things, when he was diagnosed with cancer in November 2000. He could have opted for a very major, unpredictable operation, but chose to die over the shortest possible time with as much dignity as possible, and in the process made his passing easier for everyone around him. He wrote this piece because it was in him. This was the last thing he ever wrote, and though a modest man, he was pleased with it.

Barbara Gerritse

A hymn to morphine

By Alf Gerritse

Reclining in my makeshift bed, I can oversee the Valley, from the Walton Shore to English Mountain. I am quite fortunate; in the hospital I would see a small patch of blue sky, if any at all. On occasion, my yard dog, the loyal, big lug, looks at me through the window. My poodle pet keeps closer quarters, sharing his warmth and twitchy dreams whenever possible.

Morphine is allowing me to play with the leprechauns of the mind. I think they are the same guys that used to visit when I used to smoke a joint. Oh yeah, I know (gasp), "You do drugs?" Not really, or at least not any more than those who enjoy that nicotine high or that bit of inebriation allowed by the first sip of a second drink. These little leprechauns are my friends now; when they are here the

"ugly pain-causing ones" are not.

I can see the snow on different focus levels. I can shift my depth of field, making grasslands into forest as I fly over them, and fences into lines on a matrix I have no use for. Closer by, the chickadees and nuthatches announce a pending storm with frantic feeder visits. In a little while the blue jays and mourning doves will verify these forecasts.

Yes, I enjoy being home for this. What makes it hard is when fear of pain, or pain itself, strikes, or when a hiccup threatens a respiratory arrest. There can't be a fear of death, as we don't know what to be afraid for - guilt? losing everything? No, who needs what's left? Guilt is always a late-comer, and I am happy with my slate. I have tried to be human among other humans, granting them what I have, so no problem there. Leaving loved ones is difficult, like immigration, like

before a long vacation, but acceptable knowing that there are no alternatives.

Although the year has just begun, a few more minutes of light per day require certain adjustments, announcing the return of another season. Sensitive as one is in this state, and even if premature, I can at least imagine the bulbs pushing against their earthly confines, the buds adjusting their husks to allow a slight swelling; and given a few more milligrams in a day or two, I'll be able to see the sap running through the maple trees. What more could one want? Having lived 70 years with a love of life, and life with a lust for me, I have no regrets.

There is no wind to speak of, nor is it heavily overcast; and I am sure that a single snowflake drifting down is but a leprechaun feather - did you know they had feathers?

Finally, having overcome the last "ugly guy", I am going to sleep now, perhaps to wake, perhaps not. Nothing will change. Life goes on as it has and will continue to. ❖

For Enquiring Minds - Le coin des esprits curieux

Experiences of women with recurrent ovarian cancer

By Martha Finn

The phenomenon of interest for this study was the lived experience of women with recurrent ovarian cancer. Phenomenological research methodology was chosen for this project. Phenomenology allows the researcher to focus on what it is like to be living with an experience from the subject's perspective. Current literature addressed the diagnosis and treatment of ovarian cancer. The majority of studies focused on quality of life issues. One large Canadian study (Fitch, Gray, DePetrillo, Franssen, & Howell, 1999) identified the informational and supportive care needs of women with

ovarian cancer. The author's study focused on the experiences of women with recurrent ovarian cancer.

van Manen's (1990) method of reflection and writing guided the inquiry. Six women who were within two to 20 weeks after their recurrence participated in the study. Data were collected using a structured interview guide. The interviews were tape-recorded and transcribed verbatim. Interviews lasted approximately one hour. Four of the participants were then interviewed a second time because issues arose from the initial interview. Analysis of the data revealed themes of: a) my cancer is back; b) it means that I will die; c) talking about it; d) we are people, we are not a disease; e) information;

and f) life has changed/life hasn't changed. This study of the experiences of women with recurrent ovarian cancer emphasized the importance of having their stories heard, their lives valued, and their issues validated by others. Future research to explore the experiences of a larger group of women with recurrent ovarian cancer is warranted in order to address their unique needs. ♦

Martha Finn, RN, BScN, MEd, is currently a nurse clinician for the gynecologic oncology group at Hamilton Regional Cancer Centre in Hamilton, Ontario.

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