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Editorial / *Éditorial* :
The Human Genome Impact on Health-Care Services: Are Nurses Prepared?
Laurie N. Gottlieb

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Le Point : Le processus décisionnel

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EDITORIAL

The Human Genome Impact on Health-Care Services: Are Nurses Prepared?

The future is upon us. How many times have we heard about inventions or practices that sound more like science fiction than reality, figments of a creative individual's imagination, only to become commonplace practices and integral aspects of our life and lifestyle? As I look around my own house I see many things that did not exist in my childhood — dishwasher, microwave oven, computer, CD player. Similarly, when I began my nursing career the notion of keyhole surgery, laser surgery, MRIs, and PET and CAT scans, and even electronic thermometers and blood pressure monitors, did not exist.

This situation applies not only to objects and techniques but also to biological concepts. The terms *genetics* and *genes* were not part of nursing's lexicon. In high school biology I learned about Mendel's experiments with pea plants and the principles of chromosomal inheritance. At university I read about Watson and Crick's discovery that DNA was a double helix. However, we never even considered that this knowledge might eventually be used to transform the practice of medicine and have a far-reaching impact on the practice of nursing.

It takes about 40 years for cutting-edge ideas to find their way into mainstream thinking. The first application of our knowledge of genes took place in the early 1970s, in the screening for carriers of the defective genes involved in sickle-cell anemia and Tay-Sachs disease. In both of these cases, the disease was a simple, single-locus gene alteration with readily identified and unique genetic changes. For most inherited disorders, however, the underlying genetic alterations would have to wait until the start of the sequencing of large portions of the human genome, which culminated in the mapping of the entire human genome. And it took the discovery of polymerase chain reaction (PCR), a technique that allows for the amplification of DNA, for scientists to be able to carry out the actual sequencing. This knowledge has opened up an entirely new level of understanding about how gene alterations can contribute to disease, and the application of this knowledge has revolutionized and will continue to revolutionize the practice of medicine, and subsequently the practice of nursing.

The idea of identifying gene alterations that can increase the risk for such complex diseases as cancer and heart and blood disorders is gaining wide acceptance. Increasingly, people are being genetically screened in order to determine whether they are carrying specific gene mutations that will increase their risk for a specific disease or disorder. The knowledge that a person carries the gene shifts medical practice from diagnosis and treatment of the disease, to prevention, early detection, and *then*, if necessary, treatment. For example, up until now cancer care has consisted of early diagnosis and treatment, with most of nursing's attention being focused on caring for individuals and their families after diagnosis. With the ability of medical science to identify individuals at risk, the future of health-care services lies in preventing cancer. To what extent are nurses being provided with the knowledge and skills to play an active role in this future mode of health-care delivery? How well do nurses understand the genetic basis of disease?

In looking back, one can see that changes in health-care services have often originated with discoveries in the basic and applied sciences. These discoveries have changed medical practices, which, in turn, have required nursing to change. Because nursing has often been at the end of this chain of events, its role has been reactive rather than proactive. It has been unaware of the new developments in science and therefore has been hampered in predicting and preparing for the future.

However, nursing is no longer in this position, because information on scientific developments is no longer the purview of just a few. Thus, nursing has an opportunity to alter the sequence of events and become one of the architects of future health-care services. But nursing will be invited to the table only if it has something unique to offer. Our research programs must anticipate the new directions and ask the type of questions that will contribute to new insights into how practices such as genetic screening affect people's health. Our research programs need to address such issues as how readily available genetic information can be used to promote and maintain the person's health, and how the experience of living with the knowledge that one carries a specific mutation affects the person and his or her family.

Central to nursing has been our ability to influence the person-environment interface. The genome project is making us rethink the nature of this interface. We must be prepared to rise to the new challenges.

Laurie N. Gottlieb
Editor

Decisions That Matter: Recognizing the Contextuality of Decision-Making

Franco A. Carnevale

The rise of individualism in modern Western societies has given rise to a conception of the self as an autonomous self-determining decision-maker (Carnevale, 1999; Taylor, 1989). It is commonly assumed that human agency involves conscious, deliberate action: given sufficient information, each person ought to be capable of rationally and freely choosing among decisional options. This view assumes a computer-like cognitivism whereby decision-making essentially consists of data management and decision-tree management (Dreyfus & Dreyfus, 1986). Yet people make choices that seem rationally incomprehensible: some teens choose to start smoking, many adults engage in unprotected sex with unknown partners, some adults ignore frightening lumps on their body, many men dismiss recurrent chest pains, and so on.

Decision-making is a much more enigmatic phenomenon than cognitivistic individualism would have us believe. Decisions about matters that are highly meaningful are significantly shaped by the contextual phenomena within which such decision-making is practised (Carnevale, 1998). Human action is not as independent as the ideals of the West suggest.

Rather, an individual person is acting within what Charles Taylor calls "a horizon of significance" (1985, 1989). The substantive significance of things, formal and informal decisional hierarchies, and obligations regarding traditions, among other contextual phenomena, are shaped by socio-cultural communities within a particular time and place. Thus the meanings attributed to particular decisions, and how the substance of such decisions matters, cannot be determined by individual persons. Such decisions are enacted within a contextual horizon of significance.

The inescapable contextuality of decision-making is highlighted by the papers in this Decision-Making theme issue. In their examination of self-care decisions in chronic illness, Paterson et al. report that the perceived meaning and significance of such decisions are dependent upon disease-specific timeliness, biomarkers, social context, healthy practices, and available information. Rodney et al. have found that ethical decision-making among nurses is oriented towards a particular moral horizon, in concert with currents that favour or impede such movement. Degner's Discourse piece challenges the "illusion of control" with regard to cancer-treatment decision-making, suggesting that numerous phenomena (such as limitations on available resources) covertly constrain the accessibility of some options. Wells et al. describe their successful implementation of an integrated discharge-planning decision-making model, structured with discursive rules in order to balance pragmatic and moral imperatives. Chambers-Evans highlights the complexity of surrogate decision-making by family members striving to foster the autonomy of patients who can no longer decide for themselves. McCleary argues that the ethical principle of equipoise (a state of genuine uncertainty about the relative merits of two or more treatment options in a clinical trial) is difficult to sustain because nurses providing care need to believe that they are giving their patients the best possible care. Hurlock-Chorostecki reports that nurses' decisions regarding pain management, in patients undergoing weaning from mechanical ventilation, are influenced by their a priori beliefs about pain and their role as caregivers.

These papers highlight the constellation of contextual phenomena that underlie decision-making — that is, decisions are at least as expressive of the circumstances under which they are made as the preferences of the individual making them. This also suggests that very few "truths" regarding decision-making are universalizable. Prudence should be exercised in attempting to determine whether the findings from one context are generalizable across contexts — such universalizability will need to be demonstrated. The contextuality of decision-making calls for studies that seek to "thickly" describe the social, cultural, and historical conditions under which particular decisions are made.

I have argued elsewhere that decision-making must necessarily be examined using methodologies, such as ethnography, that seek to understand the context of human agency (Carnevale, 1997). Ethnography does not rely exclusively on self-report data, which provide little insight into extra-individual phenomena related to these data. Rather, the data are examined in light of participant observations

that seek to uncover the horizons of significance against which decisions are made. These could include community beliefs, customs, practices, rituals, tacit knowledge, social structures, and power relations.

A recognition of the contextuality of decision-making can also help bridge the longstanding divide between nursing knowledge derived from clinical practice and nursing knowledge acquired through research. In everyday practice, nurses are commonly faced with the particularity of human actions (such as decisions). Understanding such actions requires an understanding of the corresponding circumstances. Accordingly, research studies of decision-making should attend to such particulars by ensuring that the decisional context is incorporated within the scope of such studies. This will enable a more sound recognition of how decisions matter.

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Discourse

Ethics and Decision-Making: Lessons from the "Cancer Wars"

Lesley F. Degner

North Americans, when healthy, hold to the widespread belief that they would want to be involved in making decisions about their medical treatment if they were suddenly to be diagnosed with a life-threatening illness. This belief is conditioned by the prevailing culture of "take control," which emphasizes the role of the individual in determining his or her own fate. The belief is perhaps most developed in the United States, where the purchase of health-care services is possible and where, by purchasing the "best" services, you could think you might actually be able to dodge the bullet of disease and disability. The need to believe that one actually has a degree of control over health-related events is deeply rooted and implies that one's survival may in fact be determined by the strength of character and resilience one demonstrates in the face of catastrophic events. Nowhere are these beliefs better illustrated than in the "cancer wars."

In 1970 President Nixon declared War on Cancer. I remember being a young graduate student at the University of Washington in Seattle when this announcement was made, to much excitement across the United States. Those of us studying in the field of cancer nursing shared this excitement, perhaps naively. While the past three decades have seen impressive gains through reduction of disease morbidity and mortality in certain types of cancers, most notably and thankfully in those that strike children and young adults, it is still the case that half of individuals diagnosed with cancer will die from their disease. The surface implication of this statistic is that no matter what one does in the face of a life-threatening disease such as cancer, the chances of dying from the disease are significant. Why, then, bother to become involved in treatment decision-making, to lobby for the right to do so, to seek out

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the best treatment available? New studies are shedding some light on the public need to "take control" over treatment decision-making during the cancer trajectory.

The work of our research team and that of others have documented an interesting phenomenon: before being diagnosed with cancer people believe they would want a high degree of control over treatment decision-making, but immediately after being diagnosed they are less inclined to seize the opportunity to make their own treatment decisions (Degner & Sloan, 1992). Certain groups of individuals clearly prefer to leave treatment decisions to their physicians, particularly those who have low levels of education, those who are over 70 years of age, those who are male, and those who are experiencing a high level of disease severity (Cann, Hack, & Degner, 2002). But then, as the years pass after initial diagnosis and treatment, the cancer "survivor" reverts to the stance of wanting to be very actively involved in treatment decision-making should he or she be faced with serious illness once more (Hack, Degner, Watson, & Sinha, submitted). This phenomenon supports the hypothesis that people newly diagnosed with cancer would want fairly active involvement in decision-making if they were not immobilized by fear and that we are justified in evaluating coaching interventions to help them gain a higher level of participation than might otherwise occur because of their diagnosis-induced decisional "paralysis." The question of whether or not this hypothesis has substance requires more study through large clinical trials, but preliminary evidence is promising (Davison & Degner, 1997). There may be an important role for nurses in helping individuals achieve their preferred level of involvement in treatment decision-making.

But the real question is: does participation in treatment decision-making at time of diagnosis really improve one's chances of survival? A recent large review found no empirical evidence to support this hypothesis, and indeed found no studies on that question in the context of cancer (Cann et al., 2002). There is evidence that people who participate more actively in decision-making at time of diagnosis have better psychosocial functioning at follow-up, as documented in British women with breast cancer (Fallowfield, Hall, Macguire, & Baum, 1990). But even trying to answer this question in a meaningful way is difficult. We know that the best predictor of participating in decision-making is educational level (Degner et al., 1997), which is closely related to income. Is participation in decision-making just a "marker" for higher socio-economic status, which in turn is associated with better psychosocial functioning? Even within the context of a life-threatening illness such as cancer, do people function better, including taking a more active role in

treatment decision-making, as a result of having more personal and economic resources? Studies conducted by the Manitoba Centre for Health Policy demonstrate that place of residence is a strong predictor of premature mortality, even within a publicly funded health-care system (Frohlich, Fransoo, & Roos, 2001).

The difficulty in documenting the characteristics of disease and treatment — the critical intervening factors in examining the relationship between participation in decision-making and survival — has clearly inhibited psychosocial researchers from studying this question. Perhaps the only context in which the question could be studied is that of a pre-existing clinical trial for a medical intervention, but such trials recruit very few patients from naturally occurring populations of differing types and stages of cancer, and so their results would hardly be generalizable. Until these design difficulties are addressed, it is unlikely that we will be able to answer the question of whether or not participation in decision-making is predictive of survival from disease. This is clearly a research question that can be answered only by groups of investigators working together at the edges of their disciplines.

Why is it so important that we address this question? Because there is an underlying assumption that the answer to the question is "yes." This assumption influences the behaviour of very important groups in our society, as evidenced in my own province, Manitoba, where a major inquest was held into infant deaths that occurred after cardiac surgery. The view that parents could have prevented the deaths if only they had more information about the surgeon prevails, and has resulted in the institution of a mechanism whereby members of the public will be able to readily access information about their physicians. But in a health-care system where individuals do not control the availability of specialists and where most members of the public do not have the resources to travel across the border to seek such services, treatment decision-making is actually shaped by recruitment and retention of specialized health-care providers in the various provinces. In my own field and in my own province, shortages of medical oncologists and radiotherapists, and the lack of specialized oncology nurses to provide transition services that in the United States are proving to save lives (McCorkle et al., 2000), severely limit the real and meaningful participation that newly diagnosed cancer patients can have in maximizing their survival. Would you want your elderly parent to receive transition services between home and hospital by a specialized oncology nurse if you knew that such services would enhance your parent's chance of survival? You probably would. But could you access such services? As long as you cannot, real and meaningful options are limited.

If these issues are not recognized and addressed, the need to study patient participation in treatment decision-making becomes somewhat superfluous. If important options that could maximize survival are not available in our health-care system, why study patient participation? In more and more cases, there is no real choice — defined as availability of evidence-based interventions — because resources, including nursing resources, are severely limited. In spite of this we create the illusion that there is a choice. Whether this illusion really helps people facing life-threatening illnesses to deal with their disease and treatment remains to be seen.

I recently had the opportunity to discuss with an American nursing colleague the struggle she went through when her son was diagnosed with Hodgkin's disease at the age of 20. First-line chemotherapy based on the most recent trial results was provided at one of the leading cancer centres in the United States, but the disease returned within 6 months. The boy then underwent "salvage" chemotherapy and a stem cell transplant, which was approved by her health insurance. She said the most difficult moment was when she and her son, who of course were reading the medical record to keep themselves informed, read that the transplant brought with it only a 5% chance of cure. But they reframed this terrifying statistic to think: why could he *not* be in the 5%? Luck and hope still play a very important role in the cancer wars. Five years later her son is alive and, more importantly, enjoying life, and she is immensely relieved and grateful. We have an illusion that we are "in control," but are we really? Ethics and decision-making at the individual level are becoming less relevant as targets of study, while the same topics at the system level are becoming increasingly relevant. The next generation of studies will need to tie these two solitudes together, so we can determine the extent to which policy decisions that expand or contract the real options available to patients impact their quality of life and survival.

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The Family as Window onto the World of the Patient: Involving Patients and Families in the Decision-Making Process

Jane Chambers-Evans

L'approche selon laquelle les membres d'une famille peuvent défendre les droits d'un patient ou agir en son nom lorsque celui-ci n'est pas en mesure d'exprimer ses volontés n'est pas remis en question. Cependant, les méthodes utilisées pour favoriser la participation des membres d'une famille dans le processus décisionnel font encore l'objet de débats. Les décisions peuvent être complexes et l'environnement dans lequel elles sont prises peut s'avérer chaotique, alors que l'approche décisionnelle des cliniciens peut souvent être perçue comme froide. Les familles sont aux prises avec le lourd fardeau émotif que leur confère leur rôle et les cliniciens s'efforcent à traduire des données complexes en des termes compréhensibles, explicites et concrets. Il faut donc examiner la pratique clinique afin d'identifier les approches les plus appropriées quant à la participation des membres d'une famille, autant sur le plan philosophique que sur le plan pratique. L'article explore les multiples facettes du rôle décisionnel conféré à une personne représentant un patient et suggère une réorientation des modèles actuels de la relation professionnel-délégué.

The need to involve family members as patient advocates and as surrogates when patients are unable to speak for themselves is not an issue. What continues to be debated are the methods for involving family members in the decision-making process. Such decisions can be complex and the environment in which they are made can be chaotic, while clinicians' approach to decision-making is often seen as insensitive. Families struggle with the emotional burden of their role and clinicians struggle to translate complex information into comprehensible, meaningful, and practical language. There is a need to examine clinical practice to determine which approaches to involving family members are preferable from a philosophical as well as a practical point of view. The paper explores the many facets of the surrogate decision-making role and suggests a reorientation of current models of the professional-surrogate relationship.

> During the war, I met my wife. She and I were the only ones left of our families — can you imagine, no one left but us? Now, 53 years later, I look at her face in that bed and I see all we have been through, the courage that has sustained her all her life, the wonderful mother she has been, and I am reliving our life together. We are so bound together that I know that once she is gone I will not be far behind. Our souls would cry for each other.

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At some point in the not-too-distant future, the clinicians working with this man and his wife will approach him and begin to discuss treatment options, perhaps even broaching the subject of withdrawal of therapy. The patient, frail and sedated, will be unable to participate in the discussion. The team will turn to her husband, frail and grieving, and ask him to help them reach a decision. Multiple factors, such as age, stage of illness, ability to comprehend, patient and family history, and the sensitivity with which the subject is broached, may affect the husband's ability to respond and work with the team to ensure that the treatment goals and decisions reflect the values and beliefs of the patient.

The role of family members as surrogates continues to be discussed, debated, and challenged. The literature to date does not reflect consensus on the role of the family and on the most effective methods for including family members as surrogates.

Clinical interventions to include patients and families in end-of-life decision-making will be enhanced if they are based on a thorough understanding of the debates and challenges. Comprehensive, compassionate interventions must be founded on the many issues that face family surrogates and the clinicians who seek to assist them in that role.

The purpose of this article is to examine the role of family members as surrogate decision-makers. The discussion begins with a brief review of the current legal and bioethical standards for decision-making. While most patients assume that their family members will be able to speak on their behalf if they become incompetent or incapacitated, the research findings are discouraging. And while most health professionals support a role for families in patient advocacy, they have difficulty articulating the means by which the family might be included in the many facets of care. The discussion then moves on to the need for a reorientation of thinking towards a concept of the patient and family as a single entity and the many challenges that such a concept poses. The discussion concludes with an analysis of methods for enhancing the relationship between health professionals and family members. The literature suggests that a shared decision-making framework can lead to the kind of partnership that will promote the well-being of the whole family.

A Framework Ready to Be Challenged

The process of decision-making in end-of-life situations can be seen as a triangle, its three sides meeting but not necessarily interconnecting (see Figure 1). One side represents a legal and bioethical framework that has championed the well-being and autonomy of the incompetent/inca-

pacitated patient using the substituted decision-making standard as a means of preserving autonomy. Another side represents clinicians who are aware that their work with patients should include family members but have little training and sensitivity in this regard. A third side represents the surrogate decision-makers who are being asked to take on more and more responsibility for decision-making but are often isolated from the process until called upon to make a "quick and dirty" final decision.

Figure 1 *Current Decision-Making Model*
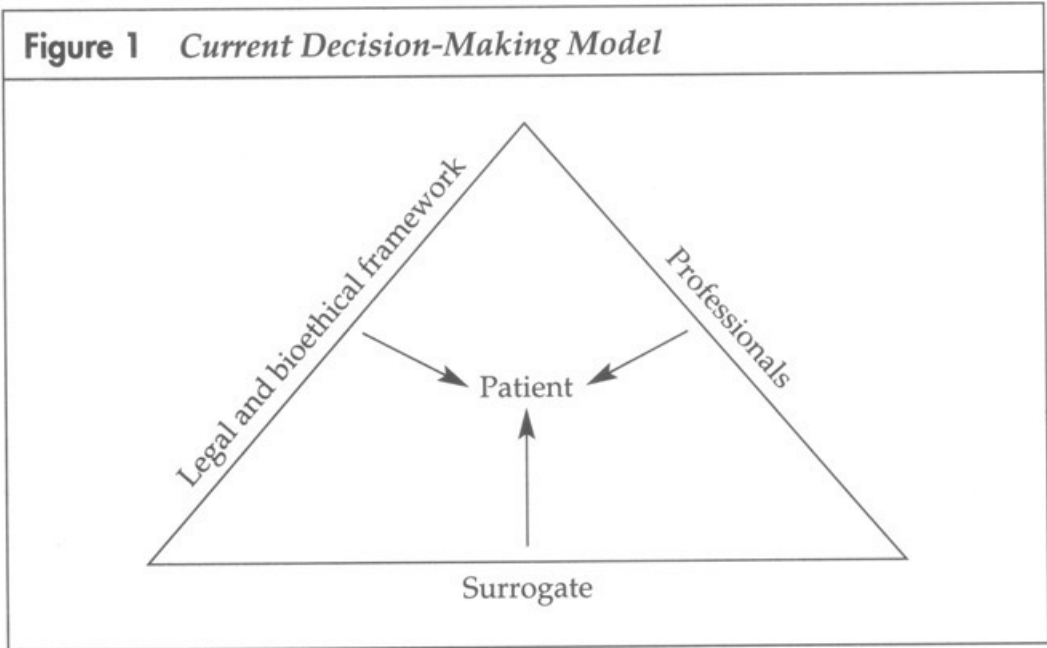
Often, professionals and patients or surrogates work in parallel or are even at odds with each other. Frequently as well, insufficient time and energy are spent in making sure that information shared has been understood, and in working with the surrogate to orient the goals of treatment towards the values and beliefs of the patient. Discussions in a time of crisis are fraught with tension and can end with both professionals and surrogates wondering if they have done the "right thing." These factors leave the patient somewhat isolated from the process and, sometimes, from the decisions being made on his or her behalf. Each of the sides of the triangle will now be discussed and a reorientation of the process suggested.

Legal and Bioethical Standards of Decision-Making

The first side of the triangle represents the bioethical and legal frameworks on which clinical decision-making rests. The patient who is ren-

dered incompetent or incapacitated by an illness or its treatment, while remaining a person worthy of respect, will be unable to speak on his or her behalf. Clinicians must continue to seek to discern the patient's wishes, based on their values and beliefs. The treating team will call on the identified surrogate to assist in making decisions on the patient's behalf. If the patient has prepared an advance directive, the team and the surrogate will be guided by the information within. If the patient has not done so, treatment decisions will still have to be made.

It is part of Canadian culture to expect that if one is unable to make decisions due to incompetence or incapacity, one's family members will speak on one's behalf. Family is usually defined as including those bound not only by blood but also by relationship, interdependence, fidelity, or long-term commitment (Blustein, 1993; Hardwig, 1990; Jecker, 1990; Nelson & Nelson, 1995; Wright, Watson, & Bell, 1996). What is not covered in law, clinical practice, or social upbringing is how one actually goes about fulfilling the role of surrogate decision-maker.

Current legal jurisprudence and bioethics literature suggest that a surrogate be asked to make decisions using a Substitute Decision-maker Standard, an approach based on knowledge of the values and belief systems of the incompetent patient. Surrogates using this "substituted judgement" approach are expected to "reach that decision which the incompetent patient would have chosen had he or she been competent" (Freedman, 1999, p. 79).

The Substitute Decision-maker Standard assumes that family members and other substitute decision-makers have intimate knowledge of the values and beliefs of the patient and an innate ability to articulate his or her express wishes (Buchanan & Brock, 1989). It appears to be based on a belief that the surrogate's insights into the character and nature of the patient will be sufficient to preserve the notion of self-determination. However, some authors argue that it is impossible to put oneself into the shoes, let alone the mind, of another person without the benefit of an advance directive (Buchanan & Brock; Suhl, Simons, Reedy, & Garrick, 1994).

If no explicit wishes have been expressed, or if the patient's wishes are not known, the Best Interest Standard may be the most logical and feasible choice for surrogates and clinicians. Buchanan and Brock (1989) note the significance of the word "best" here, as with this method the decision-maker endeavours to determine the most appropriate, acceptable, and important interest of the patient, then acts accordingly. The patient's "best interest" is a mechanism for protecting his or her auton-

omy. The Best Interest Standard differs from the Substitute Decision-maker Standard in that the surrogate does not act based on the patient's known, or even assumed, wishes, but rather attempts to determine "the medical course of action most likely to maximally contribute to the patient's welfare" (Freedman, 1999, p. 79).

The Substitute Decision-maker Standard places an enormous burden on the surrogate. Some authors express concern about the many pressures that surrogates must endure: financial burden, cultural and religious conflict, emotional stress, fatigue, power struggles with professionals, and difficulty understanding complex medical treatments, medical technology, or the medical system itself (Ellman, 1990; Freedman, 1999; Hardwig, 1990; Keyserlingk, 1997; Pinch & Spielman, 1990). The intimacy of the family unit also suggests that the illness of one of its members becomes a shared experience, as roles, responsibilities, and support networks shift and change. These issues, together with clinicians' tendency to overlook the impact on the surrogate, make it difficult to understand how substitute decision-making can benefit the patient without placing an overwhelming burden on the surrogate. In the face of such difficulties, how can patient-centred decisions be assured?

Professionals Working With Surrogates

The second side of the triangle represents the dilemmas that face clinicians as they struggle to reach decisions on behalf of their patients. Without personal knowledge of the patient's values and beliefs, and often with little knowledge of the relationship between the surrogate and the patient, a clinician may be reluctant to accept evidence, whether direct or indirect, of the patient's express wishes. The competing roles of professional as patient advocate and family member as patient advocate may lead the clinician to demand a very high standard of evidence. The focus in health-care education on the absolutes of evidence-based decision-making may further lead a clinician to consider any data, even written directives, that have not been collected by the clinician as subject to bias and potential conflict of interest.

While there is legal and bioethical consensus that surrogates must be included in decision-making if patients are unable to speak for themselves, there is little consensus on the nature of the relationship between the professional and the surrogate as a representative of the patient. The debate on this subject is outlined below.

Hardwig (1990) expresses the opinion — challenged by other authors in the bioethics field — that it is naive to view the family as defender of the patient's autonomy, that family members, by virtue of their intimacy and interconnectedness with the patient, have interests of their own that should be factored into any decision. He argues that the health-care system has focused solely on the needs of the patient and largely ignored the implications for and burden on the family. While the patient merits special attention, Hardwig argues, the family is highly implicated in many of the decisions that are made on the patient's behalf. He suggests that any new medical ethic should be based on a principle of equality whereby "the interests of the patients and family members are morally to be weighed equally; medical and non-medical interests of the same magnitude deserve equal consideration in making treatment decisions" (p. 7).

This type of reasoning can be challenged on many counts. In our present health-care system, with its shortage of both human and material resources, the ability of caregivers to develop a relationship with the patient, let alone a number of family members, is being eroded, making the chances of "knowing" even more remote.

Hardwig's most serious criticism of current thinking is that it does not adequately reflect the prevailing collective form of decision-making. Patient autonomy viewed purely as self-determination should be reserved for decisions that affect only the patient. He suggests that an appropriate way of ensuring a more equitable process would be to avoid "asking a family member to pretend that her interests are somehow irrelevant. Rather, the best safeguard would be candidly to admit the moral relevance of the interests of other members of the family and then to support the family through the excruciating process of trying to reach a decision that is fair to all concerned" (1990, p. 10).

While clinical work with families as surrogates is clearly moving in the direction of a larger decision-making role for families, Nelson (1992), as a counterpoint to the above argument, suggests that while the patient should be obliged to consider the impact of his or her decision on the family, and the family should be intimately involved in decision-making, the process can become cumbersome, particularly if the family cannot find a voice of consensus (p. 11).

Blustein (1993), in a critique of Hardwig's (1990) ideas, agrees that the current perspective of the family needs modification but does not support complete equalization of their rights. He is of the view that a communitarian conception of the patient and family, in which they are

interrelated and interdependent, better reflects the reality. In a communitarian approach, the patient would remain the "decisional locus of control," with the family playing a more familiar mentor, facilitator, or supporting role. The emphasis would be not on fairness and autonomy but on decision-making within the frame of a "community," where mutual respect and love ensure that the individual is protected within his or her own circle.

Blustein (1993) acknowledges that the picture of family he describes may be somewhat idealistic: "Even in extremely close families, patients may have different priorities from their loved ones and assess life choices in disparate ways, and these differences may surface in disagreements about how and even whether patients should be treated" (p. 11). Such differences could be mitigated, he suggests, if the role of the health-care team were expanded to include the facilitation of discussions between patient and family.

The standard interpretation of surrogate decision-making as little more than a courtesy to the family may be the result of ignorance on the part of clinicians who have been socialized into a "patient autonomy" approach. Clinicians are often reluctant to speculate about the outcome of a condition for fear of being wrong and losing the family's respect, or causing them to lose hope and their ability to cope. Families, on the other hand, often seek certainty or guarantees on which to base their decisions, yet rarely can a clinician predict the outcome with 100% accuracy. Because of these two layers of fear, there may be only an illusion of truth in conversations between clinicians and families, with pertinent information sitting under the surface.

A reorientation of professional thinking away from a patient-autonomy approach and towards a patient-centred approach may be necessary. In such an approach, the patient would be considered within the context of his or her social group of intimates. As part of the patient's development, well-being, and, ultimately, death experience, such intimates cannot be excluded or marginalized. This approach may be facilitated by dialogue that focuses on the patient, but only in the context of his or her lived experience, which includes the circle of intimates. Placement of the patient within a circle of intimates does not suggest an equalization of the rights or considerations of all those within the circle. Blustein's (1993) criticisms of the notion of equalization of rights are valid: as with most family situations, at times the needs or concerns of the patient will take precedence, while at other times these will have to be balanced against the needs and values of the group.

Surrogates Struggling With Their Role

The third side of the triangle encompasses the numerous factors that make up the role of surrogate. Many authors have discussed the practical challenges faced by surrogates. Despite the concerns expressed by both surrogates and professionals, the patient's family is still considered the prime decision-maker. However, it is not uncommon for families to be torn by the desire to hold on to their loved one and the desire to end the suffering. These overwhelming feelings can make it difficult for them to reach any decision for fear of making the wrong one and causing more suffering.

Despite research evidence showing that only a small percentage of persons rendered incompetent or incapacitated have actually talked to their family members about making decisions for them (Sawchuk & Ross-Kerr, 2000), the assumption persists that family members, spouses, and in some cases physicians will "know" how to speak on patients' behalf and will accurately reflect their wishes. Several studies have found that faith in the ability of a surrogate to do so may be misguided.

Research has shown that there is discrepancy between the choices of patients and their surrogates, on the one hand, and the choices of physicians, on the other, in the same cases. One study found that physicians were more likely than family members to withhold care that the patient would have wanted (Seckler, Meier, Mulvihill, & Cammer Paris, 1991). This study and others (Hare, Pratt, & Nelson, 1992) found that while family members were more accurate than professionals in interpreting patients' wishes, there was still a significant difference between the responses of surrogates and those of patients.

Discrepancies in congruence have been attributed to patient fear of burdening or prolonging the suffering of family members and family fear of seeing the patient in pain (Hare et al., 1992), and to types of treatment or stages of illness (Sulmasy et al., 1998). It has been found that intimacy or longevity of relationships does not necessarily increase congruency (Pearlman, Uhlman, & Jecker, 1992). It has also been found that, in the face of terminal illness, demographics such as age, ethnicity, or religion, relationship of the patient to the surrogate, the presence of an advance directive, or surrogate's perceived level of comprehension of patient's wishes do not affect congruence between patient and surrogate. Factors that have been found to increase the congruency and accuracy of decisions include a higher level of education, previous conversations with the patient, life expectancy of less than 10 years, no

personal experience (on the part of the surrogate) with a ventilator, and not attending church (Sulmasy et al., p. 624).

Sawchuk and Ross-Kerr (2000) found that very few patients had shared their preference for resuscitation with their family (16%) or their doctor (7%). This one factor appears to be key in much of the available research. Face-to-face communication seems to be the essential element in a family's ability to accurately reflect the wishes of the patient. Even the existence of an advance directive is not useful for the surrogate, it has been found, if the surrogate is unaware of it or if there has been no discussion of its contents. This finding may be related to the fact that advance directives are often broad, vague, and unspecific. For this reason families may not find them helpful.

It is obvious, then, that membership in the patient's intimate circle does not guarantee that a person will have sufficient knowledge to fulfil the role of surrogate. In addition, the decision-making process will have to be reoriented, to allow the surrogate to work with the team in determining patient-centred treatment goals, particularly if discussions have not been held with the patient. A new focus with patients, encouraging discussion with, and inclusion of, surrogates in health-care decision-making throughout the course of an illness trajectory, may also be necessary.

Reorienting the Decision-Making Process

As indicated in the literature and in the most widely recognized decision-making standards, it is not always easy for the clinician to know how to involve the surrogate, family or otherwise, in the decision-making process. The reluctance of both professionals and surrogates to face what may be a very unpleasant reality — a vegetative state, a severely compromised life, or the prospect of a difficult death — could mean that these issues are rarely even up for discussion. There may be genuine reluctance on the part of both parties to use the language of future outcomes or to focus on disability for fear of dismissing or being disrespectful to the patient — perhaps complicated by a fear of failing in one's obligation, whether professional or familial, to the patient (Freedman, 1999).

Despite the concerns, it is a reality that clinicians, the courts, and most importantly patients want and expect family members to become involved in the decision-making process. Recognition of the need for patient surrogates and the need to ease the decision-making burden has prompted a search for solutions.

Although advance directives are seen as one solution to the problem of inaccuracy and incongruency, the literature shows that few Canadians have completed such directives (11%) (Sawchuk & Ross-Kerr, 2000; Singer, Choudry, Armstrong, Meslin, & Lowy, 1995) or have had an opportunity to follow them (Gordon & Shade, 1999; Sawchuk & Ross-Kerr), while one American study found little follow-through on intention to discuss and document advance directives (Hare et al., 1992).

Slomka (1992) suggests a process of working towards a mutual understanding of both medical problems and patient preferences. While some might argue that this is in fact the current practice amongst physicians, nurses, and family members, Slomka favours a scenario of shared meanings of options and potential outcomes over a scenario in which the family has input but bears little responsibility for the results. Research consistently shows that patients are not discussing end-of-life issues with their families. If medical residents and nurses were educated in the advantages of raising these issues early on, and were provided with the skills to approach the subject sensitively, then patients might be encouraged to take the next step. Urging patients to talk to family members about end-of-life issues will not become common practice until the treating teams have developed more ease with talking to patients about them.

Freedman (1992, 1995), in his writings on competence and informed consent, expands on the concept of patient-family discussions. He suggests a reorientation away from the current focus on such legal concepts as risk, benefit, burden, and competence, and towards a broader dialogue that would include an examination of the patient's values and beliefs as well as the practicalities of the disease and the treatment options. Such a dialogue would promote an understanding of not only the illness and its impact, but also the consequences of the different treatment options for the well-being and life goals of the patient and family. Many clinicians lack the skills to participate in, much less lead, such discussions.

The idea of "sharing" information is a particularly interesting one. Sharing suggests a give and take of not only information but also feelings, opinions, and ideas. This is not an approach that most clinicians have been trained in. In general, in fact, clinicians have been led to believe that it is not only unnecessary but wrong to share too much information with patients, as they will not be able to understand it.

I began this article by identifying three sides of a discussion triangle — a bioethical framework of substituted decision-maker, clinicians

with a need to alter their approach and philosophy, and a surrogate —
usually someone who is playing the role for the first time. The patient
seems isolated from the process when there is little interaction amongst
the various players (see Figure 1). What if one were to alter the triangle
and make it a circle? If one chose to work with the patient and surro-
gate as a single entity and place them at the centre, and make the
purpose of the discussion patient-centred treatment goals and deci-
sions, how would this affect the methods and the cause of preserving
the patient's well-being and self-determination?

The President's Commission (1982) described an historical shift
over the preceding two decades in philosophy towards the patient,
from a philosophy of "medical paternalism" to one of "patient sover-
eignty." In medical paternalism, the physician is the dominant figure in
the relationship, with both the right and the responsibility to make deci-
sions in the best interest of the patient. In patient sovereignty, on the
other hand, the patient is assigned full responsibility for and control
over all treatment decisions, with the practitioner acting as the patient's
servant, sharing information and knowledge but exerting no influence
over the decisions of the patient (p. 36). Neither of these philosophies
— polar opposites in both orientation and outcome — has produced a
satisfactory relationship between the patient and the practitioner.

What is needed is a philosophy in which the decision-making
process is at the centre of the continuum, midway between medical
paternalism and patient sovereignty. The reality is that there is little
understanding of what constitutes "shared" decision-making. Profes-
sionals and surrogates, as representatives of the patient, enter into the
decision-making process as bearers of two different but equally impor-
tant bodies of knowledge. The professional brings information on the
patient's health/illness status, while the patient/surrogate brings infor-
mation on the patient's values and beliefs, which are pivotal to discus-
sions about the impact and consequences of treatment outcomes and
the establishment of patient-centred goals.

Several studies have dissected end-of-life decision-making in an
attempt to find ways of facilitating the process through shared decision-
making. In two recent articles, Charles, Gafni, and Whelan (1997, 1999)
break down the process of shared decision-making into three distinct
steps: information exchange, deliberation on treatment options, and
selection of a treatment option. In a shared process, information
exchange is a two-way flow between participants (Charles et al., 1999).

The second step, deliberation on treatment options, is what sets a
shared process apart. This step is characterized by an expectation of

exchange, of sharing preferences, both medical and personal, of inter-acting on the choice of a treatment option, and of the consequences of decisions for all parties. Frequently it is at this point, or even earlier, that the family begins to share in decision-making and the patient decides who will participate in the process (Charles et al., 1997, p. 687). Effective deliberation calls for an environment of trust such that the patient and family members are able to participate freely and feel that their concerns, questions, and recommendations are a legitimate and valuable part of the process. A key factor at this stage is the physician's ability to share in the thinking processes behind the options chosen and make appropriate recommendations without unduly influencing the decision-making process.

The final step in a shared decision-making process is the actual choice and implementation of a plan for current and possibly future care. The deliberation process entails a shared decision with specific goals that all parties are comfortable with and, in fact, are invested in (Charles et al., 1999, p. 658).

The concept of deliberation merits further examination, as it is a key element in the process of shared decision-making. Clinicians need to know what elements are most important to the establishment of patient-centred decisions. There are few studies examining the process of surrogate decision-making, yet such research can greatly enhance the ability of caregivers to work with surrogates in a meaningful way.

Swigart, Lidz, Butterworth, and Arnold (1996) began the arduous task of identifying the role of the surrogate decision-maker by inter-viewing family members of 16 patients as they struggled with "letting go," or "becoming willing to forgo life support for their relative" (p. 484). They describe three distinct steps in a family's process of "coming to terms": (1) understanding and reframing the critical illness, (2) reviewing and revising the perceived life story of the patient, and (3) maintaining family roles and relationships (p. 485). Each of these steps involves interactions with professionals and with other family members. The first step, which is key to the family's ability to take on a surrogate role, involves seeking comprehensible information, under-standing the course of the illness, and developing a relationship of trust with the caregiving team, especially the patient's physician. Swigart et al. describe this configuration of processes as "believing, ordering and integrating information received from the external environment" (p. 487). The second step is a life review focused on "the meaning and the course of the patient's life and...what the patient would have valued in this situation" (p. 488). The final step is one of "fulfilling of roles of

responsible and caring family members, and attending to how the situation could affect family relationships thereafter" (p. 489). Because human beings live in reciprocal relationships within social networks, families both influence and are influenced by an illness experience (Wright et al., 1996). Family members are often struggling with their role as advocate or decision-maker, their emotional attachment to the patient, and their own responses to the disease and the ever-present illness experience (Swigart et al.; Wright et al.). For most families, there is a seeking of mutual agreement on family issues, a seeking of consensus on decisions, and a concern for others in the family network (Swigart et al., p. 489). For some, consensus-seeking is a way of sharing the burden or blame for decisions taken.

Within the discussion of deliberation, the elements described by Swigart et al. (1996) might be considered essential to the discovery of who the patient is and how the proposed treatments will "fit" with the patient's values and beliefs and ease the decision-making burden. Since the processes of understanding and reframing the illness, reviewing and revising the patient's life story, and maintaining family roles and relationships call for interaction between family members and professionals, they are components of deliberation (see Figure 2). Charles et al. (1997, 1999) maintain that professionals must become actively involved in the process of deliberation. In light of the elements identified by Swigart et al., active engagement must include interpretation on the part of both the professional and the surrogate. According to Wright et al. (1996), family members are often so focused on the "description" of the illness — symptoms, tests, diagnosis, drugs, and so on — that they are unable to, or are not encouraged to, move on to a discussion of the illness "experience" for the patient (p. 61). This can also be a factor in the discussions between family and professionals as outlined above. If one or both parties to the discussion are unable to "see or know" the current or projected future reality for the patient, it will be difficult for them to have a legitimate conversation about ongoing care. Interpretation of the sort described will require a relationship of trust, as defined by Charles et al. (1997). The relationship itself is as important as the information to be shared and deliberated on.

Practice Changes to Enhance Shared Decision-Making

One important factor in the development of the shared decision-making approach is that the chaotic, sterile, disjointed clinical practice environment will have to be altered. As the "walk-in clinic" model of care, in which one rarely sees the same physician or nurse twice, becomes more

Figure 2 *Patient-Centred Deliberation Model*

Professionals

Legal and bioethical framework

Maintain roles/relationships

Deliberation

Patient/surrogate

Patient-centred treatment goals/decisions

Patient/surrogate

Patient/surrogate

Life review

Health/illness status review

Professionals

Professionals

Legal and bioethical framework
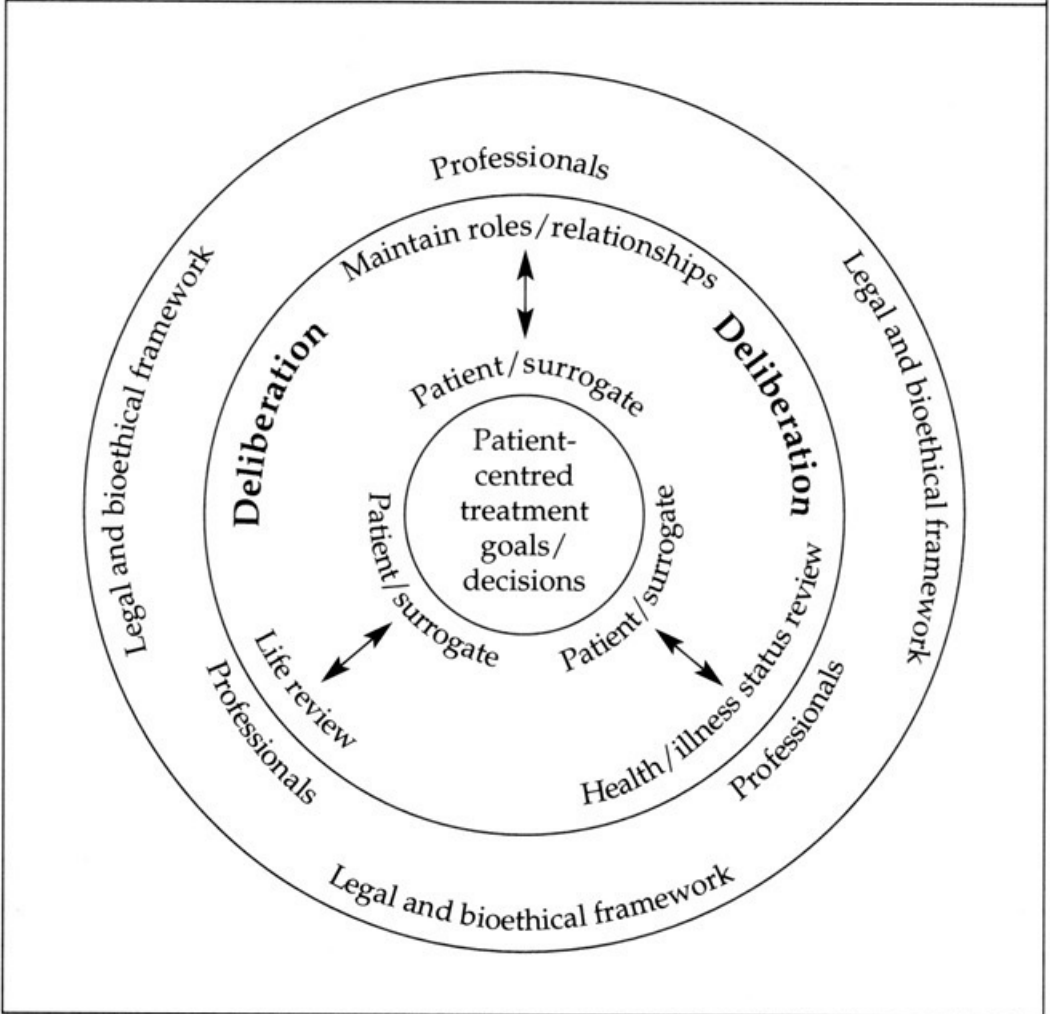
and more prevalent, the difficulty of having connected, meaningful patient/surrogate-focused deliberations will only increase. The changing-physician phenomenon, while the norm for most wards and clinics, is not reflective of the caregiving team. With the exception of the physicians, the professionals on health-care teams do not change, possess the necessary professional skills, and are already providing support, care, and advice to patients and surrogates.

One way of resolving the changing-physician issue would be to establish small interdisciplinary teams to work with specific patient populations, such as the aged or those with a chronic or a terminal illness, over time. Keyserlingk (1997) proposes a more systematic team approach that would lift the burden of responsibility for one professional to provide the type of support and leadership described above. He argues that medical institutions consistently under-use and,

perhaps, under-value the caregiving team. Both nurses and physicians feel they are patient advocates, but within the functioning of the team they often work in parallel rather than in synchronicity. Team synchronicity facilitates the sharing of information, skills, and perspectives and prevents duplication of work with patients and families. This type of work requires an atmosphere of trust among professionals, which, Keyserlingk argues, has not yet developed nor been fostered by institutions, to the detriment of both patients and professionals (p. 130).

Members of a team would need to be trained together and to be committed to the patient/surrogate-centred approach. Planning with the patient/surrogate would include deliberations as described above, always with both short-term and long-term consequences in mind.

While psychosocial assessment and interventions with patients and families has long been a foundational component of nursing education programs, and while the expectation that an intervention will benefit both patient and family is recognized in the nursing code, the nurse's role as a patient and family advocate has been underdeveloped.

Although psychosocial intervention has not historically been a focus in medical curricula, over the past decade communications skills and an appreciation of socio-economic, ethnic, and cultural influences have become essential for the physician. While efforts are being made to provide such training for medical students, in reality it is still often seen as a necessary evil or as an add-on, as opposed to an essential component of practice. Medical students and residents lack the appropriate role models — physicians who have integrated the psychosocial component into their practice and are able to teach the requisite approaches and skills.

The consistent challenging of the roles of health-care professionals and their relationships with patients and families will help clinicians to work with patients and surrogates in an open, compassionate fashion and do much to diminish conflict and champion the values and beliefs of the patient. The role of each professional on the caregiving team will need to be examined by the team as a whole so that expertise can be recognized and duplication avoided. Much will need to change for many of the professionals involved, for a patient/surrogate-focused process is not yet the norm.

Patient-centred treatment goals and decisions depend on a process of patient-centred deliberation. The relationship of trust necessary for deliberation is grounded in a shared decision-making process. Examining and capitalizing on the expertise of various team members,

and the continual development of their deliberation skills, will be key to involving surrogates in the process of patient-centred treatment decision-making.

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Author's Note

Management of Pain During Weaning from Mechanical Ventilation: The Nature of Nurse Decision-Making

Christina Hurlock-Chorostecki

Malgré leurs connaissances poussées en matière de douleur et du soulagement de la douleur, les infirmières œuvrant en soins de phase aiguë interrompent la médication anal-gésique pendant des périodes prolongées, soit avant et au cours du processus de sevrage. Des infirmières affectées à ce service ont été interviewées (n = 10) dans le but de com-prendre l'importance de la gestion de la douleur pendant le sevrage ainsi que le che-minement décisionnel dans le cadre des interventions de soulagement. Utilisant la théorie à base empirique comme méthode de recherche, l'auteure a constaté que le cheminement décisionnel relevait d'un processus dynamique et continu d'identification de données, de leur interprétation et d'action, le tout influencé par les croyances des infirmières concer-nant (1) l'existence de la douleur et l'importance de la gérer, et (2) le rôle du personnel infirmier. La théorie issue de cette étude possède le potentiel d'influencer l'élaboration d'interventions qui mèneront les infirmières à prendre des décisions efficaces, éclairées et fondées sur une approche holistique, pour soulager la douleur chez les patients en sevrage de ventilation artificielle.

Despite extensive knowledge of pain and pain management, critical-care nurses com-monly withhold analgesia from patients for extended periods prior to and during weaning from mechanical ventilation. Nurses working in critical care were interviewed (*n* = 10) to gain insight into the importance of pain management during weaning and the nature of decision-making in pain management. Using the research method of grounded theory, the author found decision-making to be a dynamic and continuous process of knowledge gathering, knowledge interpretation, and action, influenced by nurses' beliefs concerning (1) the existence of and importance of managing pain, and (2) the role of the nurse. The emergent theory has the potential to guide the development of interventions in which nurses make effective, holistic, competent decisions about pain management during weaning from mechanical ventilation.

Mechanical ventilation and weaning from mechanical ventilation are associated with pain. It has been documented that patients endure pain from diseases, injuries, surgical incisions, prolonged immobility, endo-tracheal-tube positioning, suctioning, the insertion and maintenance of specialty lines, and other invasive procedures while also undergoing the process of weaning (Jenny & Logan, 1996; Puntillo, 1990). While health professionals are well versed in aspects of pain and consider the

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management of pain to be an ethical obligation and the patient's right, it is common and accepted practice for critical-care nurses to withhold pain medication prior to and during weaning from mechanical ventilation. Since nurses are the gatekeepers to analgesia and to the management of pain for the mechanically ventilated patient, exploring the nature of nurse decision-making related to pain management during weaning is important to the nursing profession.

Literature Review

A search of the literature using electronic databases revealed no studies pertaining to the management of pain during weaning from mechanical ventilation. Comments in related literature such as "withholding analgesia in preparation for weaning was a common finding" (Stannard et al., 1996) and "promoting comfort was only occasionally mentioned as a factor affecting weaning" (Clochesy et al., 1997) suggest a need for research into the nature of critical-care nurses' decision-making related to pain management during weaning.

Research indicates that pain is recalled by critically ill patients (Holland, Cason, & Prater, 1997; Puntillo, 1990). Studies of recollection indicate that patients recall having pain "almost always" and that the intensity of the pain recalled is moderate to severe (Carroll et al., 1999; Puntillo). Patients express frustration with their inability to communicate the pain experience during mechanical ventilation and state that nurses should "just assume that it hurts" (Puntillo).

Studies conducted on critical-care nurses' management of pain illustrate a clear pattern of findings suggestive of consistent undermedication. It has been reported that critical-care nurses administer 30% or less of the prescribed analgesia to their patients (Carroll et al., 1999; Kuberberg & Grubbs, 1997; Maxam-Moore, Wilkie, & Woods, 1994; Tittle & McMillan, 1994). Comparison studies indicate that critical-care nurses administer less analgesia than surgical nurses and less than patients in patient-controlled analgesia (Caroll et al.; Tittle & McMillan).

Decision-making concerning analgesia administration in critical care is a complex process. Decision-making research indicates that nursing decisions are influenced by factors such as "knowing the patient," "personal knowing," the ability to balance interventions, and nursing skill or experience. Tanner, Benner, Chelsea, and Gordon (1993) suggest that knowing the patient is a significant element in decision-making, affecting the manner in which critical-care nurses refine the selection of patient cues. Jenny and Logan (1994) concur, commenting

that nurses feel less sure of their judgement when they do not have specific knowledge of the patient. Jenks (1993) describes personal knowing as an influential factor in one's ability to communicate within complex health-professional hierarchies. The need to balance interventions, such as those for pain management, with interventions for weaning to effect optimal nursing care is commonly cited in the literature (Clement & Buck, 1996; Stannard et al., 1996). Benner (1984) found that decision-making improved with experience: experience provided a frame of reference for nurses, allowing them to rapidly identify a problem and analyze it in relation to past situations.

The fact that critical-care nurses commonly withhold analgesia during weaning and view this as acceptable practice suggested that an examination into the nature of nurse decision-making related to analgesia administration during weaning was warranted. The purpose of the present study was to address the following two questions: What is the nature of nurses' decision-making related to pain management during weaning from mechanical ventilation? What are nurses' perceptions of the importance of managing pain during weaning from mechanical ventilation?

Methods

Design

A qualitative design was selected based on the lack of published research on nurse decision-making related to pain management during weaning from mechanical ventilation. Grounded theory was selected because the focus of the study was understanding a human behaviour process. The theoretical basis of grounded theory is symbolic interactionism. Symbolic interactionism is individual development of behaviour, or construction of reality, from symbols realized through interaction with others. The purpose of grounded theory is to generate explanative theory of human behaviour. Methods of grounded theory as described by Chenitz and Swanson (1986), such as theoretical sampling, line-by-line coding, constant comparative analysis, memoing, categorizing, and attaining saturation, were used for this study.

Sample

Following ethical approval by the hospital, ventilator-certified critical-care nurses who worked full- or part-time in the intensive care unit (ICU) of a moderate-sized urban Canadian hospital were invited to participate in a semi-structured interview. All interviews were audiotaped. An initial convenience sample was attained by inviting staff to par-

ticipate in the study and scheduling interviews. Further participants were recruited through theoretical sampling related to level of skill acquisition. Theoretical sampling is a process whereby participants are selected in an effort to achieve a reasonably balanced sample relative to the needs of the study and participant knowledge of the topic. The final sample size was 10.

Data Collection

Prior to each interview, the participant signed a consent form, completed a demographic instrument, and rated personal nursing skills. Nursing skill was rated using a short document based on Benner's (1984) levels of acquisition (see Table 1). To verify personal skill ratings while maintaining confidentiality, the researcher asked the manager of the ICU to provide a skill rating of the entire ICU staff. The ratings were compared and were found to be similar.

Table 1 *Levels of Skill Acquisition*	
Novice	Has very limited experience with patients who are being weaned from mechanical ventilation. Goals and tools of patient care are unfamiliar.
Advanced beginner	Has limited experience with patients who are being weaned from mechanical ventilation. Overall characteristics, such as weaning success indicators, can be identified from previous experiences.
Competent	Has worked with mechanically ventilated patients 2 or 3 years. Is able to cope with and manage changes in the patient. Conscious, deliberate planning of the weaning process takes place.
Proficient	Has worked with mechanically ventilated patients more than 3 years and has the ability to recognize whole situations. Knows typical events that can be expected during weaning from mechanical ventilation and recognizes deterioration or patient problems and modifies plans prior to explicit changes (such as vital signs).
Expert	Has an intuitive understanding of weaning each patient from mechanical ventilation. Has a deep understanding of the whole situation and can zero in on a problem quickly and accurately.
Source: Adapted from Benner (1984).	

The interview began with the statement "Tell me about your nursing activities when caring for your patient during weaning." Participants were encouraged to tell their own story. Probing questions were used to clarify statements and expand on information. The topic of pain management was not probed until after it was raised by the participant.

Data Analysis

Analysis of data was conducted by the researcher. The interviews were transcribed verbatim using the computer program QSR NUD*IST 4.0, designed for qualitative analysis. Constant comparative analysis of the data included reading, rereading, and comparing the transcribed interviews in order to identify similarities and differences. Line-by-line analysis, or coding, of words, phrases, and sentences was carried out to establish emerging categories. Interviews were continually compared and coded. By the seventh interview it was obvious that the data were becoming repetitious, confirming data gathered in the earlier interviews. At this time, theoretical sampling was used to ensure a heterogeneous sample and to determine adequacy and appropriateness of the data. The remaining three interviews provided concurring and confirming data, indicating that the defined categories were substantial and mutually exclusive. At this point it was deemed that the data were saturated. Memos were kept in a log book of all the researcher's intuitive thoughts. The memos were used to build and link the categories and to link the findings to existing knowledge.

Validity and Reliability

Knowledge gleaned from the preliminary literature review and the personal experiences of the researcher as an ICU nurse were bracketed in an effort to reduce bias. Bracketing is a conscious effort to put aside the researcher's preconceived beliefs regarding the phenomenon under study. The categories were shared with the participants during the study as they emerged. Participant feedback established the validity of the coding and definitions and the reliability of the emerging interpretation. To ensure objectivity and valid coding, an expert qualitative researcher was asked to review the transcribed data. Agreement on the categories and the data saturation of each category was achieved. As the theory began to take shape, it was shared with critical-care nurses in other locations. Feedback from these nurses further supported the accuracy of the data analysis. In order to establish truthfulness, the researcher presented the final draft of the theory to the study partici-

pants after all the interviews had been completed. Their comments suggested a new appreciation of their decision-making concerns and established that a truthful interpretation had been achieved.

Results

A theory of nurse decision-making was developed around the core category of belief-based decision-making. Four major categories arose from the data, each with two distinct subcategories or nursing styles, as follows:

- Nurse beliefs about pain and sedation (the diagnostic nurse; the humanistic nurse)
- The weaning puzzle (the technical survey; contemplating the big picture)
- Nurse roles in weaning (the soldier nurse; the nurse advocate)
- Managing comfort and weaning (steps towards extubation; anything for success)

The Categories

***Nurse beliefs about pain and sedation: The* diagnostic nurse *versus the* humanistic nurse.** This category includes comments that describe a nurse's beliefs or values in relation to pain. The participants quite openly described their beliefs concerning the existence of pain during weaning. Their descriptions were emphatic and reflected well-established beliefs. The *diagnostic nurse* expressed a belief that pain is a function of the patient's medical diagnosis. This belief was established prior to the nurse's contact with the patient. In relation to weaning, the belief was that pain does not exist. One nurse stated:

> *Pain? I wouldn't think so. That would always depend on their diagnosis. If they've had a lobectomy or a pneumonectomy possibly, but I don't think that there's any actual pain.*

Diagnostic nurses represented all levels of skill acquisition.

The *humanistic nurse* expressed a basic belief that pain exists when the patient indicates that pain exists. These nurses did not have established beliefs about pain, based on diagnosis, but, rather, expressed an openness to patient cues. The a priori beliefs of the humanistic nurse included a belief that pain likely exists during weaning but that this is determined by the person who is being weaned. One nurse commented:

> *We do a lot of things to patients in here that cause pain. Just from lab work they have pain. They have pain from having a tube down their throat for weeks. It's got to hurt. When we suction them, we choke them. It's got to hurt. Sometimes you even get blood. I think they all have pain.*

Level of skill acquisition did not denote a tendency to the humanistic style of nursing practice.

Two important facts emerged in this category: (1) beliefs about the existence of pain were well established a priori, and (2) level of skill acquisition had no bearing on a critical-care nurse's selection of nursing style.

***The weaning puzzle: The* technical survey *versus* contemplating the big picture.** In this category, the nurse's words or phrases suggested a search for the salient aspects of the patient, or the pieces of a puzzle:

> *We look at the big picture and see if the puzzle all fits together. If there are some things that aren't going to fit into that puzzle today, we don't [wean].*

The participants described two distinct approaches to identifying the salient aspects of the patient.

The *technical survey* describes the approach of getting to know the patient by monitoring technological and behavioural indicators and the reports of health-care professionals:

> *Basically, just the patient's vital signs and how they physically look to you. Their gases obviously would reflect whether they are having problems.*

The technical survey approach was used by nurses of all skill levels. However, those nurses who were less skilled and those who tended towards a technical approach in general placed more value on these cues than other nurses.

Contemplating the big picture describes the approach of getting to know the patient by stepping back to look at the whole picture, getting to know the patient personally, and using intuition. The nurses who took this approach viewed the patient as an individual and as a whole entity rather than in terms of separate functional entities. One nurse commented:

> *You have to remember that they are all individual people and they have a personality. I think we tend to forget and we read monitors and numbers.*

The focus of this approach was the patient, and it allowed for a broad, holistic interpretation of cues. Another nurse described it this way:

Just standing at the bottom of the bed and taking a look at her...stepping back. Sometimes that's a little more important, I find.

Humanistic nurses tended to contemplate the big picture. However, the degree to which this approach was taken depended on skill level. The more-skilled nurses placed greater value on the whole patient.

***Nurse roles in weaning: The* soldier nurse *versus the* nurse advocate.** This category includes perceptions about the role of the nurse during weaning. The participants expressed clear perceptions about expected nurse behaviours and described two distinct role beliefs. The *soldier nurse* plays a submissive role, exhibiting behaviours such as reporting to a higher authority, following orders, and maintaining a position within a chain of command. One nurse commented:

If it's a physician's order, you have no decision to make when it comes to not giving analgesic or whatever.

The nurses who fit this description participated in decision-making in a passive manner. While one might expect to find less-confident nurses in this role, nurses at all skill levels were found to fit the description of soldier nurse.

The *nurse advocate* uses the team structure to troubleshoot patient needs, challenging team members' ideas and decisions and collaborating with them to produce a plan of care. One nurse stated:

Sometimes you have to go up to the doctor and say, "OK, things are going pretty good except for the guy is as anxious as hell and he's getting bronchospastic and the tube is driving him crazy, so could we just give him a little bit [of analgesia]?"

The participants who described their role as that of nurse advocate had the highest level of skill acquisition. Their descriptions suggest active participation in decision-making as a result of their perceived role as an equal member of the health-care team.

***Managing comfort and weaning:* Steps towards extubation *versus* anything for success.** This category describes nursing actions *done to* and *done with* the patient during weaning. *Steps towards extubation* describes routine nursing actions *done to* patients to make them comfortable during weaning, such as positioning, mobilizing, suctioning, sedating, and explaining. One nurse described her routine:

We suction every 2 hours. We make sure the airway is clean and clear. We make sure the head of the bed is at an adequate level so that they are not having problems.

This course of action was selected by those nurses who were less skilled and those whose role belief was that of soldier nurse.

The alternative approach, *anything for success*, comprised actions *done with* the patient during weaning. These included mutual goal-setting, ensuring comfort, and communicating with the patient. One nurse commented:

> *They need to know that we are here to help them, that we are not here to judge them and we want to help them get better. If they want to have family in to support them, that is really important, that they feel comfortable. I will try to get them through it.*

This course of action was described by experienced nurses and those who expressed a belief that the nurse's role is that of advocate.

The Theory

The emerging theory may be described in terms of a circle, representing the continuous nature of the decision-making process (see Figure 1). Four concentric circles, or lines of decision-making, are divided into six wedges, or phases. The circles indicate skill level, with the inner circles representing the *more skilled* and the outer circles the *less skilled*. For the purposes of simplification, Benner's (1984) five skill levels have been collapsed into two broad levels. In view of Benner's postulation that a major change in thinking occurs between the competent and proficient levels, the two groups have been organized as the less skilled (novice, advanced beginner, and competent) and the more skilled (proficient and expert). Each skill level has two circles, representing the two styles of nursing, *diagnostic* and *humanistic*, that emerged from the data.

Phase 1 is the point at which the nurse enters into decision-making, possessing a level of skill, a style of nursing, and a priori beliefs (concerning, for example, pain during weaning), three factors that will set the nurse on a specific line of decision-making.

Phases 2 and 3 are when "knowing the patient" takes place. In phase 2 patient cues are selected according to skill level, style of nursing, and a priori beliefs. This selection varies from the purely technical (the technical survey) to the holistic view (the big picture). In phase 3 the identified cues are interpreted. The context within which the interpretation takes place depends upon the nurse's level of skill, style of nursing, and a priori beliefs. In this study, cues were interpreted in the context of the patient or the process of weaning.

Figure 1 *The Belief-Decision Continuum*

Phase 2 Knowing the patient (cue selection)

Phase 3 Knowing the patient (cue interpretation)

Phase 4 Role beliefs (enacts soldier role and passive decision-making *or* advocate role and active decision-making)

Legend

Impact of role belief: a change from less-skilled behaviour to the more-skilled behaviour of active decision-making

Impact of role belief: a change from more-skilled behaviour to the less-skilled behaviour of passive decision-making

Reversion to original, a priori beliefs

ENTRY

Phase 1 A priori beliefs (impact on cue selection and interpretation)

less-skilled diagnostic
less-skilled humanistic
more-skilled diagnostic
more-skilled humanistic

Phase 6 Reversion to original line of decision-making (beliefs remain unaltered)

Legend

Outer circles = less skilled
Inner circles = more skilled
Diagnostic nurse
Humanistic nurse

Passive

Active

Phase 5 Action

In phase 4 the nurse's role beliefs impact on decision-making, potentially generating a shift to an alternative line of decision-making. Belief in the nurse's role as soldier or advocate will determine whether the nurse will participate passively or actively in the decision-making process.

Phase 5 is the action phase. While level of skill, style of nursing, a priori beliefs, and "knowing the patient" influence the choice of action, the greatest influence is the belief about the role of the nurse.

In phase 6 the nurse returns to the original line of decision-making, as the power of the role belief diminishes once the action has been completed.

Discussion

The findings from this study suggest that nurse decision-making related to pain management during weaning is a continuous, dynamic process. The continuous cycle was described by the participants as knowledge generation, knowledge interpretation, and action selection. Knowledge in this instance is the information that a nurse gathers and interprets about the patient, while action is the intervention the nurse selects as the appropriate response to that knowledge. This cycle reflects problem-solving as part of the nursing process.

The findings suggest that driving forces move the process forward through varying levels in the circle. Both the nursing process and the skill level play a part in this dynamic process. Consistent with Benner's (1984) theory, experience was shown to influence the means by which the nurses gathered and interpreted knowledge about the patient. For example, those who used the broadest scope of knowledge gathering and interpretation were among the most experienced nurses. Two powerful forces outside of the nursing process and skill level were identified as major driving forces: a priori beliefs about the existence of pain and beliefs about the nurse's role during weaning.

The first force encountered in the decision-making process is the nurse's perceptions about the importance of managing pain during weaning. Despite published evidence that pain is experienced during weaning, more than half of the nurses in this study held a strong a priori belief that pain is not experienced during weaning and that analgesia is unnecessary. Beliefs about whether pain exists during weaning have a significant impact on patient care. A nurse who believes there is no pain will approach the patient for knowledge, and interpret that knowledge, differently from a nurse who believes there is

pain. This finding is congruent with that of Greipp (1992), whose study of ethical decision-making found nurse beliefs to be a potential inhibitor, enlightening or biasing the nurse and affecting his or her approach to the patient. The *diagnostic nurse* identified in the present study, for example, holds an a priori belief that pain does not exist during weaning and therefore does not perceive pain management in weaning as important. The diagnostic nurse approaches the patient for knowledge within the limited frame of weaning. Cues sought, and interpreted, are related to the patient's tolerance of the weaning process. Pain cues are not considered in the search for or interpretation of cues, even though they may be there. The result could be that weaning is stopped due to intolerance when, in fact, the patient was in pain, and the pain could have been managed.

A second force arises in the decision-making process after patient cues are interpreted and before an action is selected. This is the belief about the nurse's role in weaning a patient. The perception of the nurse as a *soldier* or as an *advocate* determines whether the nurse will be a passive or an active participant in decision-making. The nurses who perceived a soldier role deferred or delegated decision-making to other members of the health-care team, thereby participating passively. In the context of pain management during weaning, the soldier nurse who does not administer analgesia because of an "order" transforms the act of withholding analgesia from an ethical issue of managing pain into a legal issue of following orders. What is most interesting about this belief is its power. A humanistic nurse who believes that pain exists during weaning, and identifies and interprets the patient's pain cues, will not advocate for analgesia administration if his or her role belief is that of soldier. While Benner (1984) describes advocacy as a characteristic of the more skilled nurse, the findings of the present study suggest that perceived role exerts greater power than skill level in determining advocacy. Although the participants who described an advocacy role for nurses were among the most skilled, not all nurses at the highly skilled level perceived such an advocacy role. The impact of role beliefs on patient care is significant in that most of the nurses did not advocate for the best care for their patient. Role beliefs may be compared to Ajzen and Fishbein's (1980) normative beliefs. While their theory of reasoned action was developed to predict health behaviours, normative beliefs resemble role beliefs in that in both cases the opinions of individuals and groups determine whether a nurse will or will not perform an act. The motivation to comply, another aspect of normative beliefs, was discussed by the nurses in the present study: they described motivators for the soldier role as perceived lack of control over personal

practice and caregiver stress. Role belief can ultimately result in an intervention that is in contradiction to beliefs about the existence of pain and knowledge of the patient. As powerful as it may seem, role belief does not possess the ability to alter the nurse's belief concerning an issue. It is for this reason that, prior to continuing the process of decision-making, the nurse will return to the original belief set.

Implications for Practice and Future Research

The emerging theory of nurse decision-making provides a means for critical-care nurses to examine their practice specifically in relation to pain management during weaning and generally in relation to their personal beliefs and decision-making role. The theory provides a new perspective on forces that influence decision-making among critical-care nurses. The finding that critical-care nurses rely more heavily on established belief systems than on empirical evidence when making decisions about care has implications for personal practice, nursing education, and critical-care orientation programs. In their personal practice, critical-care nurses can use this theory to identify their personal belief on an issue and review the literature to determine whether evidence-based knowledge credits or discredits that belief. It may be that the method of knowledge-dissemination in nursing education does not impact on established beliefs. The emerging theory offers a method for determining whether education affects the decision-making process. The theory can be used in critical-care orientation programs to the benefit of both novice and mentor. The novice can be nurtured in the different styles of nursing as he or she gains experience, towards the goal of humanistic decision-making and advocacy nursing. The theory can help the mentor to appreciate the complexities that the novice nurse must negotiate in order to reach a level of technological-humanistic competence within a highly technical environment.

Concepts that form the basis of the emerging theory support those identified in the literature. These include: a continuous process of knowledge and action (Ford & Profetto-McGrath, 1994), effect of experience on decision-making (Benner, 1984), importance of knowing the patient (Jenny & Logan, 1994; Tanner et al., 1993), and impact of beliefs on actions (Ajzen & Fishbein, 1980; Greipp, 1992). Further research is needed to test the efficacy of the emerging theory for use in critical care. The truthfulness of the theory and its generalizability within nursing have yet to be tested. Concerning the influence of beliefs about a particular issue, the following areas could be examined: the impact of nursing and critical-care education on belief systems, the ability of edu-

cation to change beliefs, and the role of nursing experience in the formation of beliefs. Such research could lead to more effective knowledge acquisition by novice and expert critical-care nurses. Concerning the influence of beliefs about the nurse role, research into the role of social hierarchy in critical-care units in encouraging or discouraging advocacy could reveal ways of improving nurse self-efficacy; research into nurses' working environment could lead to a greater understanding of issues of power and control in their personal practice; and research into the effect on nurses of caring for the critically ill could provide insight into why decision-making is delegated to others and why nurses are compelled to leave critical care.

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Equipoise in
Clinical Nursing Research

Lynn McCleary

La notion d'équilibre clinique, qui désigne un certain état d'incertitude face aux mérites relatifs de deux traitements ou approches thérapeutiques ou plus, est un élément fondamental de l'éthique en recherche clinique. Le degré d'incertitude nécessaire pour qu'un essai clinique respecte les principes éthiques fait l'objet d'un débat soutenu. Ce concept d'équilibre clinique n'a pas reçu suffisamment d'attention de la part des auteures en sciences infirmières. Le présent article s'y attarde en s'appuyant sur l'expérience de l'auteure relativement à trois essais cliniques portant sur des interventions psychosociales en santé mentale. Il résume les arguments en faveur et à l'encontre de l'équilibre clinique dans l'évaluation éthique de la recherche clinique. L'équilibre clinique peut s'avérer impossible à atteindre dans le cas des essais qui portent sur des traitements psychosociaux présentant des résultats multiples pour les patients et leurs proches. En outre, la nécessité d'atteindre l'équilibre clinique pourrait placer les infirmières qui fournissent ces traitements dans une position conflictuelle, puisque pour être en mesure de donner le meilleur traitement possible, elles doivent croire que ce qu'elles font est dans le meilleur intérêt du client. Or, pour accepter la randomisation, elles doivent, dans une certaine mesure, renoncer à cette attitude. L'article présente des exemples dans le but de voir comment les écarts relatifs à l'équilibre clinique dans la position des chercheurs, des cliniciens et des participants peuvent entraîner des difficultés dans la poursuite, en sciences infirmières, d'objectifs de recherche valides sur le plan méthodologique et conformes à l'éthique.

Equipoise, a state of uncertainty about the relative merits of 2 or more treatments or therapeutic approaches, is fundamental to the ethical conduct of clinical research. The degree of uncertainty necessary for ethical conduct of a clinical trial is the subject of ongoing debate. The concept of equipoise has not received sufficient attention from nurse authors. This paper examines the concept of equipoise by drawing on the author's experience with 3 trials of psychosocial interventions in mental health. Arguments for and against using equipoise in the evaluation of ethics of clinical research are summarized. Equipoise may be impossible to achieve in trials of psychosocial treatments with multiple outcomes for patients and relatives. In addition, the need to achieve equipoise may put nurses who provide psychosocial treatments in clinical trials in conflict. In order to provide the best treatment possible, they must believe that what they are doing is in the best interests of their client. Yet, in order to accept randomization, they must, to some extent, relinquish that belief. Case examples are used to examine how discrepancies with respect to the "equipoise status" of researchers, clinicians, and research participants may be problematic in achieving methodologically sound, ethical clinical nursing research.

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Background

Equipoise is a state of uncertainty about the relative merits of two or more treatments. It is the reason we do clinical research — to resolve the uncertainty, to find out which treatment or practice is best. At first glance equipoise appears to be a simple concept, but on close examination one realizes that it is a complex phenomenon. This complexity results in controversy within the health-care community about equipoise and clinical research. The concept of equipoise has been discussed primarily with respect to randomized controlled trials. It is, however, more broadly relevant because uncertainty is fundamental to the ethical conduct of all clinical research, not only randomized controlled trials. Furthermore, while the theoretical and practical implications of equipoise in ethical clinical trials have been discussed in the bioethics and medical literature (Edwards, Lilford, Braunholtz, et al., 1998), equipoise has received limited attention from nurse authors (Nield-Anderson, Dixon, & Lee, 1999; Olsen, 2000; Scullion, 2000).

This paper examines the concept of equipoise by drawing on the author's experiences with three trials of psychosocial interventions in mental health. Various definitions of equipoise are described. Arguments for and against using equipoise in the evaluation of ethics of clinical research are summarized. Specific cases are used to show how discrepancies with respect to the "equipoise status" of researchers, clinicians, and research participants may impede methodologically sound, ethical clinical nursing research.

Theoretical Versus Clinical Equipoise

In his analysis of the problems of applying the standard of equipoise in the evaluation of the ethics of clinical research, Freedman (1987) differentiates between theoretical and clinical equipoise. Theoretical equipoise, also known as individual equipoise, is the individual researcher's state of uncertainty about the relative merits of two or more therapies. According to Freedman, it exists when "overall, the evidence on behalf of two alternative treatment regimens is exactly balanced" (1987, p. 143). When equipoise exists, a trial of the two treatments is ethical.

As noted by Freedman (1987) and others (Alderson, 1996; Chard & Lilford, 1998; Scullion, 2000), theoretical equipoise is practically untenable. It does not reflect the complexity of clinical decision-making and is disturbed as soon as the clinician or researcher *perceives* a difference — whether or not a difference exists. Clinicians are rarely in a state of

equipoise; they have opinions as to the effects of particular treatments. These opinions may be based on a variety of sources, including research literature, theory, clinical experience, intuition, and ideology. Ethical clinical practice entails providing the care that is most likely to benefit the patient. This means that in ethical nursing practice, recommendations or choices are based on the nurse's opinion. Thus, nurses who enrol patients in research may be in conflict. If a nurse believes one treatment is better than another, how can that nurse enrol a client in research where the client may not receive the preferred treatment?

The author managed a randomized clinical trial that presented this dilemma to some nurses who made referrals to the trial. The trial was a comparison of time-limited psychosocial interventions for schizophrenia. All the research participants received routine outpatient care from their primary clinicians. In addition, they were randomly assigned to either (1) family psychoeducation, (2) psychosocial rehabilitation, or (3) both family psychoeducation and psychosocial rehabilitation. Both programs lasted 4 months and were provided in the community prior to the trial (Munroe-Blum & McCleary, 1995). At the time of the trial, there was good research evidence for positive effects of family psychoeducation for families with specific risk factors. The trial was conducted because there was limited evidence for each of: (1) effects for the trial population, which was not limited to higher-risk families; (2) the effectiveness of time-limited psychosocial rehabilitation; and (3) the effectiveness of the two treatments in combination. Both treatments were accepted by mental health clinicians in the local community and there were usually waiting lists for the programs.

When the trial was introduced in the community, a number of clinicians who usually made referrals to the programs disliked the idea of randomization. The primary criticism was "We know what our clients need and what will work for them; they shouldn't be randomized." The research team's response was to present a critique of the limitations of the evidence and to remind referring clinicians of the potential benefits of the research. These benefits included the potential to avoid repetitions of past mistakes in psychiatric care, where treatments were provided based on ideology and subsequently disproven theories such as the theory of the schizophrenogenic mother. In effect, this response was designed to produce uncertainty among the referring clinicians, to move them closer to equipoise. The clinicians were presented with evidence of the existence of what Freedman (1987) calls "clinical equipoise."

Freedman (1987) proposes a modification of the concept of equipoise, which he calls clinical equipoise. Clinical equipoise is also known as communal equipoise (Alderson, 1996) and collective equipoise (Chard & Lilford, 1998). Freedman suggests that research is ethical "if there [is] honest, professional disagreement among expert clinicians about preferred treatment…[when] there is not consensus within the expert clinical community about the relative merits of the alternatives to be tested" (p. 144). Applying this standard, as long as the nurse accepts that there is disagreement among the expert community about what is best, the nurse can, in good conscience, enrol participants in a clinical trial.

Freedman's (1987) position is not without controversy. The problem is that while clinical equipoise may mean that a trial is ethical, it still may not be ethical for particular clinicians, who are not themselves in equipoise, to recommend the trial to a particular patient. This point has been argued without resolution in the medical literature (e.g., Enkin, 2000; Lilford, 2001; Lilford & Djulbegovic, 2001; Sackett, 2000a, 2000b, 2001; Weijer, Shapiro, Glass, & Enkin, 2000). The arguments apply equally to nursing practice and research. Sackett's position, argued in the Canadian and British medical literature (2000a, 2000b, 2001), is that clinical equipoise in the medical community does not let the individual clinician off the hook. His opinion is that a physician must be in equipoise to enrol a participant in a trial, that the physician cannot ethically ignore clinical judgement about what is best for a particular patient. The counter-argument is that treatment recommendations depend not only on clinical skill, but also on up-to-date knowledge of the best therapeutic strategies available, that knowledge is not developed in isolation and physicians must rely on the collective judgement of the medical community (Shapiro & Glass, 2000).

Individual Clinician Equipoise and Psychosocial Treatments

Clinical equipoise about the treatments under investigation may provide sufficient justification for the physician researcher prescribing one or another medication as part of a clinical trial. However, at least one nurse author believes that clinical equipoise is insufficient justification for nursing research because nursing involves the nurse as a therapeutic agent. Olsen (2000) argues that equipoise is reasonable in trials of interventions with a physiologic mechanism of action but not where benefit for the patient depends on the nurse-patient interaction. At the heart of his argument is a position that trials of psychosocial interventions are unethical. He believes that subjective experience cannot be

objectively measured and thus a patient's subjective experience is inaccessible to researchers. Furthermore, when the relative benefits of the intervention rely directly on subjective experience, the expert community's assessment of benefit is less valid than the individual's assessment. Thus, in Olsen's opinion, clinical equipoise is not reason enough to ask a person to forego personal preference and enter a randomized controlled trial of a psychosocial intervention. This argument may apply to trials of existing treatments, where there are sufficient resources to respond to patient choice. There are, however, practical limitations to accommodating patient choice. When resources are limited, new treatments may not be available except as part of their development and testing.

What about the nurse researcher who provides a nursing intervention as part of a clinical trial? What would uncertainty about the effects of a treatment mean for nurses who provide a psychosocial treatment as part of a trial? To some extent, a nurse's motivation and enthusiasm depend on a belief that the treatment or nursing care is beneficial. It would likely be difficult for an enthusiastic nurse to accept a randomized design.

In the trial of psychosocial treatments for schizophrenia described earlier, there was tension between "clinical equipoise" and "individual equipoise" for some of the multidisciplinary staff who provided the treatments. There was initially some discomfort with the idea of randomization. On the one hand, the clinical staff were involved and informed as the research was planned, and they understood the limitations of the empirical evidence for the treatments. They accepted both the notion of clinical equipoise and that the trial was ethical. On the other hand, prior to the introduction of the research, the clinical staff, like the referring clinicians, "knew what was best" and believed in the potential benefits of their work. This meant that there were times when a clinician was not in equipoise about a particular patient. On these occasions, there was discussion about whether the clinical staff's opinion justified making exceptions to the randomized design. The standard of clinical equipoise prevailed.

In this example, entire programs were being evaluated. In this context, if a nurse staff member had disagreed with clinical equipoise as a justification for the randomized controlled trial, or disagreed about whether clinical equipoise existed, the nurse's options would have been limited. The nurse could either work for a program that was being evaluated using an experimental design or work elsewhere. Where research involves evaluation of specific interventions rather than entire pro-

grams, it is possible for nurses to decide whether to participate as treatment providers. As well, there may be choice as to which treatment to provide. For example, ongoing research about family psychoeducation for adolescent depression (Sanford et al., 2000) involved introducing family psychoeducation as a new treatment within outpatient clinics. Nurses were in a position to decide whether to learn how to provide the new treatment and whether to participate in the trial. In a trial of group and individual psychotherapy for borderline personality disorder, the nurses and other clinicians who provided the therapy decided which kind of therapy to participate in (Marziali, Munroe-Blum, & McCleary, 1999; Munroe-Blum & Marziali, 1995).

Consideration of research ethics generally focuses on the effects of the research on patient participants. The potential effects on providers of the experimental treatments are rarely considered. One might question whether it is justifiable to produce uncertainty among nurses who provide nursing care as part of research. Shouldn't the nurses who are providing the care believe in what they are doing? Is it fair to move them towards equipoise? The answer comes down to the issue of the basis of their belief. In this era of evidence-based health care, the evidence underlying belief in the effectiveness of a particular nursing intervention is more important than the belief itself.

In addition to the possible moral implications of producing uncertainty among nurses who provide nursing care as part of research, there are practical implications for research design. Consider, for example, the development and evaluation of a telephone counselling intervention for diabetes control among adolescents. In a recent randomized controlled trial of this nursing intervention, the nurses who provided the counselling were initially very enthused about the potential benefits. As the trial proceeded, that enthusiasm was needed to maintain their motivation for the challenging work. The work required perseverance and creativity in the face of numerous obstacles (C. Richardson, personal communication, June 2001).

In the case of a hypothetical new nursing intervention, development might proceed from theory and hopefulness about its effectiveness through to pilot testing. When the pilot study has produced promising evidence, a clinical trial would be conducted. Enthusiasm for the intervention and belief in its effectiveness would build among participating nurses, perhaps even contributing to the intervention's effectiveness and intensifying the effort they put into their work. Given this scenario, what happens when the intervention is tested in a randomized controlled trial? It may be impossible to test the new intervention

fairly using a randomized design, as introducing uncertainty about the effectiveness of the intervention might compromise the nurses' ability to provide the intervention. At best, if effectiveness was reduced, then a sample size based on the effect size in the developmental research would be insufficient and the trial would be under-powered. At worst, the effect would disappear and the research results would incorrectly indicate that there was no benefit.

Equipoise in the Context of Shared Decision-Making in Nursing Practice

Another objection to randomization, one that was raised by referring clinicians in the trial of psychosocial treatments for schizophrenia described earlier, is that randomization is incongruent with the philosophies of client-centred care and shared decision-making espoused in the field of psychosocial rehabilitation and in the nursing profession. Does randomization detract from efforts to have clients involved in their own care? Similar issues have been raised by nurses (Nield-Anderson et al., 1999; Scullion, 2000) and other authors (Karla-wish & Lantos, 1997). One solution to this dilemma is already in place in clinical research. The informed-consent process ensures that the decision to participate in research is freely made. In the trial of psychosocial treatments described earlier, research participants provided informed consent. In response to their concerns about randomization versus shared decision-making, the referring clinicians were told about the process of informed consent.

Informed consent does not, however, mean that research participants can choose between treatments in a trial, based on their wishes. Another solution to the tension between randomized design and the shared decision-making model is to modify the research design to allow for patient choice within the study. For example, in a randomized controlled trial of relaxation training as an adjunctive therapy for pain management in sickle cell anemia, a research participant who had been assigned to the control condition asked to receive the relaxation training. The nurse investigators adopted a modified cross-over design to accommodate participant feedback (Nield-Anderson et al., 1999).

Theoretically, consenting to enter a clinical trial implies that the research participant/patient is in equipoise. However, there is evidence that a significant proportion of people who consent to participate in clinical trials may not fully understand what they are consenting to (Edwards, Lilford, & Hewison, 1998) and may assume that they will receive whatever treatment is deemed best for them (Alderson, 1996).

This indicates that some research participants do not understand the randomization process and do not understand that the researchers do not know what is best.

Research participants' understanding of consent for nursing research has not been investigated. However, it seems reasonable that the patient's process of arriving at equipoise and consenting to participate in research may be equally difficult regardless of whether the research is about nursing or medical practice. The challenge of ensuring that research participants are really in equipoise could be met by improving the process of informed consent. For example, Chard and Lilford (1998) suggest that decision analysis can be used to help patients make decisions about participation in clinical trials by trading off potential outcomes, their probabilities, and associated patient-specific utilities. This approach would give patient values primacy and would be consistent with a shared decision-making model of nursing.

Community Equipoise

The case for the primacy of patient equipoise in determining whether a trial is ethical is taken further with the argument that patient values must be formally considered earlier in the research process than at trial entry (Chard & Lilford, 1998; Karlawish & Lantos, 1997; Lilford & Jackson, 1995). Theoretically, community members on research ethics boards represent patient and community values in the judgement of whether equipoise exists; they ensure that "community" equipoise exists. However, depending on how community is defined, it may be that research ethics boards are insufficient and that, in order to ensure community equipoise, it is necessary and desirable to consider patient values by involving patients in study design (Karlawish, 1997; Karlawish & Lantos). To ensure that community equipoise is representative of patient values, it may be necessary to involve patients, patient advocacy groups, or patient representatives in decisions about which research questions to pursue and which research methods to use. This kind of process has been used in AIDS research, with activist groups influencing the US Food and Drug Administration to modify the process of clinical research (Epstein, 1996). Nurse researchers could (and do) involve patient organizations in discussions on research questions and design. For example, nurses planning interventions for families of people with Alzheimer's disease could collaborate with members of an Alzheimer society. Inasmuch as such members are the "community" of users of services for families of people with Alzheimer's

disease, this collaboration could produce research questions and designs that reflect community equipoise.

Family Research

In addition to the practice context of shared decision-making, nursing differs from biomedical research in that much of nursing involves work with families. Application of the concept of equipoise in research where the risks and effects differ for each family member has not been well examined. When evaluating the ethical basis of interventions that involve more than one family member, it may be difficult to weigh competing risks and benefits in order to determine which family member's interests are most important.

Consider, for example, a family education intervention for adolescent depression that is designed primarily as an adjunctive treatment. Adolescent patients, their parents, and their siblings may participate. For the adolescent, the intended benefits are reduced duration of their depression and reduced risk of recurrence. For the parents and siblings, the possible benefits include improved knowledge about depression and enhanced ability to cope with the adolescent's depression. There are potential risks. For example, among parents, increased knowledge about depression and risk of recurrence may result in prolonged anxiety for their child. Among siblings, learning about familial risk for depression may produce anxiety about their own risk for depression.

As with other kinds of psychoeducation, family education interventions for adolescent depression have been tested (e.g., Brent et al., 1997; Sanford et al., 2000). Such trials are ethical if there is equipoise about the benefits. In trials of family education for depression, there are unique risks and benefits for the adolescent patients, their parents, and their siblings. As long as the potential risks and benefits for individual family members are balanced, then equipoise is present. But what about instances where benefit to one family member is associated with risk to another family member? Does a potential benefit to, say, the depressed sibling outweigh the potential risk to the well sibling? These questions are not unique to research in this field. They are just as important in clinical decision-making on family interventions.

Conclusion

We conduct clinical trials because we are uncertain about the relative merits of one treatment over another. The degree of uncertainty necessary for the ethical conduct of a clinical trial is the subject of ongoing

debate. The British bioethicist Richard Ashcroft writes about the epistemological problems of equipoise (1999). In his discussion of the relationship among equipoise, knowledge, ignorance, and belief, he hits the nail on the head when he states that the debate about equipoise in research ethics turns on the role of belief. Differences of opinion with respect to what constitutes evidence are present in much of the debate about using equipoise as a standard for ethical evaluation of clinical research. There may be conflicting degrees of uncertainty at the level of the clinical community, the individual clinician-researcher, and the patient. This can make some research impractical, even if it is ethical.

The standard of clinical equipoise may be impossible to achieve in trials of psychosocial treatments with multiple outcomes for patients and relatives. In addition, the need to achieve equipoise may put nurses who provide psychosocial treatments in clinical trials in conflict. In order to provide the best treatment possible, they must believe that what they are doing is effective, in the best interests of their client. Yet, in order to accept randomization, they must, to some extent, relinquish that belief.

In debates about equipoise and clinical research, there are strong opinions but no easy answers. It behoves nurses to enter into these debates. We must think carefully about uncertainty and equipoise as we plan and conduct clinical research. We need to think about the implications of our choices for patients and nurses who participate in research and those who may benefit from the research.

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Disease-Specific Influences on Meaning and Significance in Self-Care Decision-Making in Chronic Illness

Barbara Paterson, Sally Thorne, and Cynthia Russell

Ce projet de recherche visait à examiner les décisions quotidiennes prises par des personnes atteintes de maladie chronique en matière de soins auto-administrés, dans le but de comparer les démarches de prise de décision suivant les différentes maladies et de cerner les critères par lesquels ces personnes évaluent la qualité des décisions. On a demandé à vingt et un sujets atteints soit de diabète type 2, de VIH/sida ou de sclérose en plaques, et choisis comme spécialistes en matière d'autosoins par leur clinicien, de consigner leurs décisions pendant une période d'une semaine; ils ont ensuite été interrogés en profondeur sur la démarche qui a abouti à leurs choix et sur les facteurs qui les ont influencés. Ce protocole a été répété de manière à obtenir des résultats significatifs et détaillés. Bien que l'on ait pu cerner certains points communs entre les participants relativement à leurs décisions respectives, des différences existent quant au sens et à l'importance qu'ils leur donnent, suivant des attributs propres à chaque maladie : opportunité, biomarqueurs, interaction avec le contexte social, conception des pratiques saines et accès aux renseignements pertinents. Les résultats ont été analysés et comparés dans le but de suggérer des orientations de recherche et des interventions éducatives susceptibles d'améliorer la qualité des décisions en matière de soins auto-administrés chez les patients atteints de maladie chronique, qui tiendraient compte de l'influence des attributs propres à chaque maladie.

The purpose of this study was to investigate the everyday self-care decision-making of individuals with chronic illness for the purpose of developing a comparison of decision-making processes between chronic diseases and to identify criteria by which persons with various chronic conditions evaluate the quality of self-care decisions. A sample of 21 individuals with either Type II diabetes, HIV/AIDS, or multiple sclerosis, who were nominated as expert self-care managers by their clinicians, recorded the decisions they made in their daily self-care over a 1-week period and were interviewed in depth to elaborate on the decisions, the processes by which they made them, and the factors that influenced them. This process was repeated to obtain depth and detail in relation to decisions and decision-making processes. The findings revealed that although participants shared similar elements in their self-care decision-making, they differed in the perceived meaning and significance of their decisions, depending on disease-specific attributes relating to timeliness, biomarkers, interaction within a social context, the construction of healthy practices, and available relevant information. Findings were analyzed and compared to suggest future directions for research and educational interventions to enhance the quality of self-care decision-making in chronic illness by considering the influence of disease-specific attributes in self-care management.

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A major challenge in the self-care management of chronic illness is the need for daily decision-making in relation to medication, diet, and other factors (Hurley & Shea, 1992). Despite the significance of this challenge, the process of self-care decision-making in chronic illness has not been a primary investigative focus (McLeod, 1998). When self-care decision-making has been studied, the emphasis has been on specific decisions such as opting for mastectomy or lumpectomy in breast cancer or responding to a disease-related symptom. Such models do not capture the uncertain, everyday decisions that individuals with chronic illness make, often in the absence of definite symptoms. Further, they provide limited information on context, available resources, or individual perception of the importance of a specific decision within the decision-making process (Hollen, 1994). The development of interventions to foster expert self-care decision-making requires an understanding of what such decision-making might entail (Hernandez, 1991; Maclean, 1991; Maclean & Oram, 1988; Paterson & Sloan, 1994; Price, 1993) — the various processes involved and the criteria that expert self-care decision-makers use in measuring the quality of their decisions. In a study with persons with Type I diabetes (Paterson & Thorne, 2000a, 2000b), we documented such processes in detail and became fascinated with the complexity of everyday self-care decision-making in relation to that disease. However, some of the characteristics of Type I diabetes are unique to that chronic disease, such as the use of a glucometer for feedback on the outcomes of self-care decisions. We therefore extended our inquiry to other chronic diseases, in order to develop a comparative analysis of the phenomenon.

The purpose of this study was to investigate the nature of self-care decision-making in chronic illness for the purpose of developing a comparative analysis of diseases and identifying patient criteria for the evaluation of self-care decision-making across diseases.

We focused our attention on individuals with self-care expertise in relation to a long-standing diagnosis of either Type II (non-insulin-dependent) diabetes, HIV/AIDS, or multiple sclerosis (MS). We selected these three specific chronic diseases because they represented the theoretical variables that might help us interpret differences among the self-care decision-making experiences. While Type II diabetes can include some of the features that were familiar to us from our research in Type I, it is typified by onset in adulthood rather than early in life, and in general it differs from Type I in both trajectory and management. HIV/AIDS was selected on the basis of its representing a rather different social challenge from that of MS or diabetes because of its infectious nature and associated stigma. MS, in contrast to both diabetes and

HIV/AIDS, is characterized by minimal medical intervention coupled with considerable lifestyle adaptation.

Research Method

Our methodological choices were influenced by two assumptions: (1) effective self-care decision-making in chronic illness serves to enhance quality of life, and (2) persons with chronic illness stand to develop expertise in self-care decision-making as they live with the disease. We therefore chose a research method that would enable us to explore self-care decision-making from the perspective of those who engage in it and to consider its multiple coexisting influences. Self-care decisions entail a "range of behaviour undertaken by individuals to promote or restore their health" (Dean, 1989).

Sample

The sample comprised 21 English-speaking individuals over the age of 18 who had been treated for either Type II diabetes, HIV/AIDS, or MS for a period of at least 3 years. These diseases were selected because they represented significant variation with regard to disease trajectory, symptomology, prognosis, treatment, and physiological indicators of the efficacy of self-care. These disease-specific attributes have been determined to influence self-care decision-making in chronic illness (Coates & Boore, 1995; McDonald-Miszczak, Wister, & Gutman, 2001; O'Neill & Morrow, 2001; Paterson, Russell, & Thorne, 2001). The sample included seven persons in each disease category. They were recruited through nomination by primary-care clinicians (such as internists or clinical nurse specialists) as meeting our selection criteria for expertise in self-care management: sufficient knowledge about their disease, the factors that might influence it, and their responses to treatment to make trustworthy self-care decisions in order to maintain or achieve acceptable levels of disease-specific indicators such as HbA1c levels in diabetes or viral load in HIV/AIDS, or symptomatic indicators such as fatigue in MS and HIV. Eligible individuals who indicated a willingness to be contacted were telephoned so that the researchers could clarify the purpose and design of the study and answer any questions. Although all participants were told that they were considered by the nominator to be experts, most expressed a reluctance to be called expert self-care managers, preferring the term "successful" to "expert." One man said: "It is not possible to be an expert, because you are always learning and there is always some new situation to deal with."

All but two of the 13 men and eight women in the sample were Caucasian. As might be anticipated by virtue of disease distribution, the participants varied on several demographic indicators (Table 1). The participants with diabetes were somewhat older and less educated than those in the other two groups, and were more likely to report co-morbid conditions, generally attributable to disease-related complications. Those with HIV/AIDS were generally younger and had more years of education. Those with MS had been diagnosed longer and were more likely to report being divorced since diagnosis. In contrast to participants with diabetes, who typically described themselves as retired, those with HIV/AIDS and MS were more likely to be unemployed and to report significant financial concerns related to their disease and affecting their self-care.

Data Collection and Analysis

Multiple data-collection methods were used to identify the process and possible influences of decision-making. These were: (1) a modified "think-aloud" technique, (2) audiotaped formal interviews, and (3) final focus group session. This combination of methods had been effective in our previous studies (e.g., Paterson & Thorne, 2000a) for eliciting in-depth data on everyday decision-making that are not readily accessible to conscious awareness and are not commonly discussed in traditional interview contexts.

The participants were interviewed immediately prior to the first data-collection period and on two subsequent occasions, within 1 week of each think-aloud recording session. The interviews ranged from 45 minutes to over 2 hours in length. In the initial interview, the participants were asked probing questions with regard to their chronic illness

Table 1	*Demographic Characteristics by Disease*		
Disease	**Age (years)**	**Education (years)**	**Years Since Diagnosis**
Diabetes	62–74 x = 66.7	9–16 x = 11.7	4–32 x = 9.9
MS	40–61 x = 50.6	10–17 x = 13.7	8–25 x = 16.6
HIV/AIDS	40–72 x = 50.6	12–17 x = 14.4	3–15 x = 9.7

experience (e.g., What was your response when you first heard your diagnosis?) as well as for demographic and disease particulars, after which the interviewer gave the participant a tape recorder and described the think-aloud method of data collection. In accordance with interpretive description methods (Thorne, Kirkham, & MacDonald-Emes, 1997), questions for subsequent interviews were generated from the analytic framework, previous interviews, and think-aloud transcriptions.

The modified think-aloud technique has been used extensively in the study of decision-making by clinicians (Fisher & Fonteyn, 1994). It has the advantage of being non-intrusive and relatively independent of the researcher's selective interpretation of what is significant to record (Paterson & Thorne, 2000a). The participants were asked to carry a voice-activated tape recorder with them for two 1-week periods over the course of 1 year. Seasonal and life-pattern variations were considered in the choice of data-collection periods, for maximal theoretical sampling.

The participants recorded their decisions regarding diet, medication, physical activity, rest, stress management, skin care, and other disease-related issues. They recorded the reason for the decision, the context of the decision (e.g., who was present), and factors affecting the decision (e.g., stressful event). They also recorded their thoughts on the action chosen (e.g., to contact the physician). Audiotapes of the modified think-aloud sessions were transcribed immediately, and post-think-aloud interviews were scheduled as soon as possible after the recording period (usually 5 days after receipt of the tape). During this interview, the participant was invited to expand upon the logic revealed in the recording and to elaborate on his or her decision-making practices. For example, one participant recorded the following decision: "It was too cold to do my usual walk today so I decided to walk around the basement until I had the same amount of sweat that I get on my walk." During the follow-up interview, the participant was asked such questions as Why did you decide to walk in the basement? How did you know that the activity was equivalent to walking outside? Are there any other activities that you considered equivalent to a walk outside? What would you have done if you couldn't walk in the basement? Although some participants provided less detail in their think-aloud recordings than others, the interview served as a trigger for them to recall further detail and reasoning. Variation in the focus of self-care decisions was evident among the disease groups (e.g., participants with diabetes tended to focus on diet, those with HIV/AIDS and MS on energy conservation).

For the final phase of data collection, the participants were asked to join a focus group attended by people with the same chronic disease. The focus group capitalizes on common themes among people with similar experiences. In the case of the present study it permitted us to test the conceptualizations derived from individuals against the expressed opinions of the group as a whole (Fontana & Frey, 1994). Three participants who were unable to attend the focus group received a written summary of the findings and were invited to comment on them individually.

In keeping with the guidelines for interpretive description, data collection and analysis were conducted concurrently using a constant comparative analytic approach. Building on our research into everyday self-care decision-making in Type I diabetes (Paterson et al., 2001; Paterson & Thorne, 2000a, 2000b), our initial analytic framework oriented this process towards consideration of components of self-care decisions, types of self-care decisions, antecedents, factors affecting decisions, and the criteria by which expertise was determined. This analytic framework provided an initial conceptual focus to the findings and an explicit basis for the evolving comparisons among disease groups.

Findings

The findings revealed that self-care decision-making is a value-laden phenomenon and that the unique nature and character of each chronic disease greatly influence the manner in which it is experienced. The participants judged self-care decisions on the basis of their appropriateness, personal meaningfulness, and significance. Although there were commonalties among the three diseases, the meaning and value attached to self-care decisions were often unique to one disease, particularly with regard to the timeliness of the decision, interaction within a social context, interpretation of biomarkers, the construction of healthy practices, and the availability of relevant information.

Timeliness

One disease-specific factor in the perceived significance and meaning of self-care decisions was their timeliness, particularly with regard to whether the outcome would be immediate, short-term, or long-term. Self-care decisions are largely immediate and short-term in Type I (insulin-dependent) diabetes, because such decisions are necessary to mediate the effect of diet, exercise, medication, and other factors on blood-glucose levels. In Type II diabetes, however, the participants' self-

care decisions were rarely immediate, because they perceived no dramatic consequences to delaying decisions. In HIV/AIDS and MS, immediate decisions were made only in relation to fatigue management or energy conservation ("I had to lie down or I'd never be able to go out later"). The other decisions were occasional (e.g., to take a trip) or one-time (to quit work; to not take a medication or to try a new medication). The timeliness of self-care decisions also affected the number of every-day decisions made within each disease group. While our previous study, among people with Type I diabetes (Paterson & Thorne, 2000a), found a mean of 21 self-care decisions per day in the think-aloud data-collection periods, the present study found a mean of 12 decisions per day in Type II diabetes, four decisions per day in HIV/AIDS, and five decisions per day in MS.

Another aspect of timeliness in self-care decision-making was perceived prognosis. In all three disease groups, self-care involved decisions around the "dailyness" of life in the context of what the future might hold. The future as shaped by the course of the disease influenced the significance and meaning of specific decisions. For persons with MS, for example, decisions forced by a change in mobility (to accept a wheelchair) or career (to take a leave from work) were emotionally charged in that they implied submitting to the progression of the disease rather than merely accommodating a temporary setback. Persons with HIV/AIDS were often aggressive and vigilant about nutrition and wellness in the early stages of the disease but shifted their priorities towards comfort and momentary satisfaction as the disease progressed. As one woman explained, "If I was dying, I'd eat anything I felt like eating." In general, their decision-making was oriented around such issues as how best to make use of the limited quality time they had left. While the participants with diabetes tended to focus their decision-making around meals and other functions in the immediate present, the threat of disease-related complications such as neuropathy eventually became a powerful motivator for considering the long-range implications of their decisions.

Interaction Within a Social Context

The participants described their disease as influencing their social interactions, and their social interactions, in turn, as determining the meaning and significance of their decisions. In HIV/AIDS and MS, for example, the visibility of the disease often exposed the participants to public scrutiny: "You can just feel them staring at you, feeling sorry for you. You start seeing yourself through their eyes and you feel

depressed." Both diseases can involve visible differences that make functioning and interaction complicated. At times, those with MS avoided moving about in public settings for fear of being regarded as "handicapped": "I won't bring my walker with me to the [church] group unless everyone there already knows I have one." Those with HIV/AIDS who had Kaposi's sarcoma avoided situations in which they might be stigmatized because of the disease: "I'm not going to the party. There will be people there who will see my spots." Some participants indicated that visibility did not affect their self-care decision-making once they were able to reframe the situation as non-threatening. For example, a woman with MS stated that at first she had "dreaded" being seen in a wheelchair because of the connotations of helplessness but had learned to view it as "a tool — and I realized fairly quickly that it…allowed me to work, continue to work."

Only those participants with HIV/AIDS consistently reported social context as a focus of self-care decision-making. For them, deciding whether to disclose their HIV status and whether to become activists by participating in the political and advocacy aspects of the disease were integral elements of self-care, because they set the conditions by which they might help to effect long-term gains for people with HIV/AIDS. In many instances, these decisions also involved self-education and research. Although individuals with all three diseases demonstrated some aspects of such participation, only those with HIV/AIDS interpreted it as central to the everyday management of their disease.

The stigma associated with HIV/AIDS influenced the meaning and significance of decisions about disclosure of the disease. The participants said that although those with HIV/AIDS may for years be quite "normal" in appearance and behaviour, they are living with a condition that has been the focus of unprecedented social fear and stigma. They differentiated, however, between the stigma of HIV/AIDS related to chemical dependency and that of "no fault HIV or poor-baby HIV," such as caused by tainted blood or homosexual practices. One participant reported that she had advised a friend with an intravenous drug addiction to say that she contracted her HIV from "a needle stick exposure, to get better treatment."

Biomarkers

Another disease-specific attribute that affected the perceived meaning and significance of self-care decisions was biomarkers, physiological indicators and symptoms typically associated with the disease.

Profound fatigue can be characteristic of both HIV/AIDS and MS. Participants with HIV/AIDS or MS therefore made many self-care decisions in relation to fatigue management and energy conservation, depending on how much they perceived the fatigue as affecting their ability to live the kind of life they wanted to live. Because fatigue tends to be intermittent in HIV/AIDS, persons with this disease often give in to it, rest, and reorganize their lives to accommodate it. In contrast, MS fatigue can be constant and pervasive, so people learn to "push through" it in order to be able to take part in valued activities. In the focus group, the participants with MS identified what they termed the "100-widget theory." They explained that MS generates a finite allotment of energy for any given day. This awareness of finite energy allotments featured in their decisions related to mobility aids and activities, since using a wheelchair could conceivably free up widgets of energy for activities that "really matter." People with MS described this monitoring of widgets as like having a "second wheel" constantly running in their heads, counting energy expenditure and warning them when they were getting close to their total daily allotment.

Participants with diabetes were the most familiar with "bodily listening," using this method and glucometers as mechanisms for fine-tuning the validity and reliability of the somatic cues for physiological status. They stated that this enabled them to detect and treat alterations in blood glucose and thus prevent diabetes-related complications from interfering with their quality of life. They also used these mechanisms to gauge the risk of eating something outside their dietary regime. In addition, they tended to evaluate the quality of their self-care management on the basis of the number and extent of diabetes-related complications they experienced: "I have some neuropathy but that's all. I think that's pretty good for someone who's been diabetic as long as I have. It means I've been looking after myself."

Healthy Practices

While all participants considered healthy practices an aspect of self-care decision-making, the construction of healthy practices differed among the three disease groups. For example, participants with HIV/AIDS and MS regarded food and nutrition as critical factors in their ability to feel as well as possible and to ward off progression of the disease or its complications. In contrast, persons with diabetes focused on eating within strict regulatory guidelines, and their self-care decision-making often related to "cheating" or being "bad" when they failed to follow their prescribed diet religiously. They were much less concerned with

nutrition than with learning how to make a "calculated cheat" by eating foods not included in their diet and how to use medication and exercise to balance this decision. Individuals with HIV/AIDS and MS were more likely to explore health foods and to avoid products that might exacerbate their symptoms, such as fatigue: "I always feel more tired after eating a piece of steak as opposed to chicken or fish." In general, individuals with diabetes were more committed to regular exercise than those with HIV/AIDS or MS, although maintaining physical strength was a concern for all groups. Persons with HIV/AIDS included healthy sexual practices in their commitment to a healthy lifestyle, particularly measures to avoid transmitting the disease. Persons with HIV/AIDS and MS included in their conceptualization of a healthy lifestyle such decisions as: to quit or control smoking, to monitor and reduce stress, to pace and time activities to conserve energy, and to prepare in advance for activities or events that had special meaning.

Information

For all three disease groups, the quantity and nature of information available about the disease and its management influenced the meaning and significance of self-care decisions, particularly decisions about consulting others and adhering to prescribed regimes. The field of diabetes is replete with current, credible information and "textbook protocols" for disease management. Consequently, although the participants with diabetes believed they had unique treatment response patterns, when new issues or problems arose in their self-care management they tended to consult diabetes specialists and to follow their advice, at least initially. If the advice did not result in a resolution, they resorted to experimenting with the prescribed regime or consulting other people with diabetes. "When they tell you this will work, you know that thousands of diabetics have tried it. I give it a try, and if it doesn't work for me, I figure things out for myself."

Although the participants with HIV/AIDS concurred that there is now an extensive database of information on disease management, they pointed out that this information is constantly changing and is often controversial. Most participants in the HIV/AIDS group used computer technology to keep abreast of the constantly changing information in relation to their disease. They stated that health-care professionals "can't possibly keep up with all that's happening in the field" and tended to "shop around" for experts in the field who could answer their questions while acknowledging their own experiential knowledge.

They also relied on each other to validate "rumours and press releases" about HIV/AIDS treatment:

> *When you have AIDS, everyone has an idea about what works and what doesn't. The doctor I have now, I rely on him to tell me about infections and general things but I wouldn't trust him with drugs — I have a pharmacist that I found on the recommendation of one of my friends who has AIDS too. And sometimes people, like your family, tell you about some herb that will cure you. I don't automatically discount it. I look it up on the Web and look for some articles on it, and I ask around the AIDS community, see what people know and what they think.*

Because MS is much less characterized by recommended treatments, persons with MS were more likely than the other participants to explore advice from a series of health practitioners and felt considerably more at liberty to accept or reject medical advice. They emphasized that they were more likely than "strangers, like the doctor" to know "what works."

Discussion

As articulated by the participants in our studies, self-care decision-making in chronic illness has both general and disease-specific features. Some of the latter influence the meaning and significance of specific self-care decisions as well as how they are made and the priority they are assigned. The specific focus of relevant decisions and the points of tension between standardized advice and individualized choice vary considerably among the disease categories, so that self-care decisions that seem quite familiar to those with one disease might be relatively unfamiliar to those with another.

Grahn, Stigmar, and Ekdahl (2001) demonstrate that meaning positively influences the motivation of people with chronic musculoskeletal disorders to use their personal resources in self-care management. They suggest that quality of life and well-being might improve if nurses, when planning for disease management, were to consider the meaning that people with a chronic disease ascribe to specific aspects of their disease. The present findings provide foundational evidence for such a conclusion in other chronic illnesses.

Our findings also support the notion that practitioners cannot assume that the experience of self-care decision-making is generic. Nor can practitioners assume that common approaches in client education and care management will be equally successful in all chronic diseases. Although our research supports the finding of Kralik, Koch, and Webb (2001) that the chronic illness experience has many common elements

across diseases, it is important for nurses to acknowledge that each disease has unique attributes that influence the meaning and interpretation of specific self-care decisions. Our findings also indicate a need for practitioners to consider not only the immediate meaning of the self-care decision for the person with a chronic disease but also how that meaning is shaped by the person's expectations for the future. Nurses, for example, should consider asking people with chronic illness from time to time how they perceive the trajectory of their disease and how this perception affects their self-care decision-making.

A caution in interpreting these findings is that the features of self-care decision-making that are disease-specific may be a product of not only the disease but also the demographic group in which it is prevalent. For example, the age differential between persons with Type II diabetes and persons with HIV/AIDS may play some role in the discrepancies in reported participation in health-care negotiation and use of technologically based information sources.

Researchers such as Kralik, Brown, and Koch (2001) and Evangelista, Kagawa-Singer, and Dracup (2001) have demonstrated that gender and personal and cultural values influence the meaning that people with chronic illness ascribe to self-care decisions and decision-making. However, this was not a focus of our research. McDonald-Miszczak et al. (2001) found that disease-specific beliefs were predictors of self-care behaviours in people with arthritis, whereas people with hypertension and heart disease were more motivated by general beliefs such as self-efficacy. If the present study had included more disease groups, particularly those that are often asymptomatic (e.g., hypertension), it may have identified additional factors influencing both disease-specific and generic self-care decisions. Therefore, although disease-specific self-care decision-making practices will continue to be of interest to researchers, it is important to ensure that the full range of factors that shape this phenomenon remain open to investigation.

Conclusion

Expert everyday self-care decision-making in chronic illness is a complex, individualized, and dynamic process. The nature and manifestations of each chronic disease determine the particular set of intellectual, social, and behavioural skills that will be developed and refined over time. In varying ways, each chronic disease presents those afflicted with identifiable challenges in interpreting symptoms, managing information, building healthy lifestyle practices, and engaging in social and health-care interactions in order to judge how best to live with their

illness. Both common and disease-specific attributes of the disease will be important elements in our efforts to uncover the inherent meaning and significance of self-care decisions and to uncover and explore the processes by which they are made.

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Navigating Towards a Moral Horizon: A Multisite Qualitative Study of Ethical Practice in Nursing

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Cet article rapporte les résultats d'une étude qualitative portant sur la prise de décision axée sur des principes déontologiques chez les infirmières. Des groupes de discussion rassemblant des infirmières travaillant dans divers contextes professionnels ont été mis sur pied pour explorer la signification du concept d'éthique et la mise en œuvre d'interventions fondées sur des principes déontologiques. Les résultats s'appuient sur la notion d'horizon déontologique (moral horizon) – l'horizon représentant « le bien », l'objectif que les infirmières ciblent dans leur pratique. Les résultats indiquent que les courants du climat moral dans lequel œuvrent les infirmières influencent de façon importante le cheminement de celles-ci vers l'horizon déontologique qu'elles visent. Bien trop souvent, les infirmières ont été forcées à naviguer contre un courant qui privilégie la biomédecine et la culture corporative. Par ailleurs, un courant favorisant le soutien entre collègues, la présence de lignes directrices et de normes professionnelles, et l'éducation déontologique les a aidées à cheminer vers cet objectif. Les implications quant à la pratique infirmière et une compréhension d'une prise de décisions fondées sur des principes déontologiques font l'objet d'une discussion.

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This paper reports the results of a qualitative study of nurses' ethical decision-making. Focus groups of nurses in diverse practice contexts were used as a means to explore the meaning of ethics and the enactment of ethical practice. The findings centre on the metaphor of a moral horizon — the horizon representing "the good" towards which the nurses were navigating. The findings suggest that currents within the moral climate of nurses' work significantly influence nurses' progress towards their moral horizon. All too often, the nurses found themselves navigating against a current characterized by the privileging of biomedicine and a corporate ethos. Conversely, a current of supportive colleagues as well as professional guidelines and standards and ethics education helped them to move towards their horizon. The implications for nursing practice and for our understanding of ethical decision-making are discussed.

The field of health-care ethics[1] has not attended to nurses' concerns very well over the four decades or so of its development.[2] Theory, research, and practice have tended to overlook or trivialize the kinds of ethical problems that nurses confront in their practice and the difficulties they experience in their role as moral agents (Chambliss, 1996; Jameton, 1984, 1990; Liaschenko, 1993a, 1993b; Rodney, 1997; Sherwin, 1992; Starzomski, 1997; Storch, 1992; Warren, 1992; Yeo, 1994). Fortunately, this is beginning to change. Health-care ethics is moving out of the dominance of the biomedical paradigm (Benner, 2000; Churchill, 1997; Coward & Ratanakul, 1999; Evans, 2000; Frank, 1998; Gadow, 1999; Hoffmaster, 2001; Kaufman, 2001; Levi, 1996; Sherwin, 1992, 1998; Winkler, 1993; Wolf, 1994) and nursing is becoming much more engaged in contemporary work on health-care ethics, as this issue of the Journal attests.

Understanding ethical decision-making[3] is an important part of understanding professionals' enactment of their moral agency.[4] That is, we ought to know how moral agents approach and deal with ethical problems in their practice. However, despite the progress made on contemporary work in health-care ethics, we still know little about how ethical decisions are actually arrived at and acted upon, and what moral agents experience when they are unable (or are able) to follow through on their decisions, what they believe the consequences are, and what they have to say about the effects of their practice environments on their decision-making (Calam, Far, & Andrew, 2000; Evans, 2000; Fox, 1990; Hoffmaster, 1990, 1999; Kaufman, 2001; Redman & Fry, 2000; Rodney, 1997; Saks, 1995; Solomon, 1995; Starzomski, 1997; Weisz, 1990).

Our purpose in this paper is to report on a recent study that sheds some light on the complexity of nurses' ethical decision-making. We will explicate our methodology and relevant findings, then use our findings to reflect on the implications for ethical decision-making, relational practice, and policy. Qualitative data such as ours have great promise for the ongoing development of theory and practice in ethics

(Hoffmaster, 1990, 1991, 1993; Jameton & Fowler, 1989; Jennings, 1990; Yeo, 1994). It is therefore our hope that what we have to say will be helpful for our colleagues in nursing as well as other disciplines.

Inquiry: Background for This Study

Focus

Our study constituted the first exploratory stage in a program of research, so our focus was quite broad.[5] Our first research question concerned the *meaning of ethics* for nurses providing direct care, for nurses in advanced-practice positions, and for nursing students. Our second research question concerned the *enactment of ethical practice* by these three groups. Finally, our third research question concerned the *integration of ethical content* in current nursing curricula. The study was therefore conducted in three interrelated parts:

Part 1: Describing community and hospital nurses' enactment of ethical practice. Qualitative data were obtained from nurses involved in direct care to gain a better understanding of the ethics of their practice. This included an exploration of the effect of the practice context on ethical decision-making and interdisciplinary team functioning.

Part 2: Understanding the role of advanced-practice nurses in fostering ethical practice in hospital and community care. Qualitative data were obtained from nurses in advanced-practice positions. The investigators explored how these nurses did (or did not) get involved in ethical practice. This included understanding how advanced-practice nurses foster ethical decision-making while providing support for nursing practice.

Part 3: Examining the integration of ethical theory in the delivery of nursing curricula. Qualitative data were obtained from students in a baccalaureate nursing program to explore their understanding of and involvement in ethical practice. This included inquiry into what students have experienced in their practice, and how this was or was not addressed through the integration of ethical content in their curriculum.

The main goal of our study was to contribute to a theoretical and practical foundation from which to promote the ethical practice of nurses. Our secondary goal was to contribute to a theoretical and practical foundation to support the ethical practice of professionals in other disciplines. While our findings were multifaceted,[6] there was a significant subset of findings related to ethical decision-making. We learned from our participants how ethical decisions were actually arrived at and acted upon, what they experienced when they were unable (or

were able) to follow through on their decisions, what they saw as the consequences of their decisions, and the effects of their practice environments on their decision-making.

Methodology and Methods

Our study was qualitative in nature and was conducted using the constructivist (naturalistic) inquiry methodology explicated by Lincoln and Guba (1985). We used focus groups as the method of data collection. This method is particularly well suited for qualitative data collection (Morgan, 1997) and has been employed successfully in a study of ethical decision-making around resource allocation (Starzomski, 1997). Moreover, the focus group has several attractive features: researcher influence on the data is limited, participants in the group tend to exercise a good deal of control, and participants can react to and build upon the responses of other members of the group, creating a synergistic effect (Madriz, 2000; Morgan & Krueger, 1993; Wilkinson, 1998). Our study benefited from all of these features. For instance, both practising and student nurses in the focus groups generated rich reciprocal dialogue. At the same time, we were aware of some of the inherent limitations of the focus-group method, including "groupthink," uneven participant contributions, and replication of organizational power dynamics in the group (Madriz; Morgan; Morgan & Krueger; Starzomski, 1997; Wilkinson). We attempted to attenuate such limitations by having at least two researchers present — one to facilitate the group process and one to observe, take field notes, and contribute as necessary. We also attempted to make our focus groups homogeneous; members of the group were usually known to each other and were not (as much as possible) in hierarchical relationships. Further, we ensured that the designated facilitator had expertise in group process and interpersonal dynamics.

Approximately half the focus groups were conducted in a midsized metropolitan area with one health region and half in a large metropolitan area with several health regions. Administrative and ethics approval was obtained from the University of Victoria and from the research ethics committee of the region in the case of the mid-sized metropolitan area and each of the regions in the large metropolitan area. Data collection took place from January 2000 to January 2001 inclusive.

Guided by a process of theoretical sampling (Strauss & Corbin, 1998), we formed 19 focus groups, for a total of 87 participants. Once research ethics and administrative approval had been obtained, nurses from the identified clinical areas were invited to participate in focus

groups through a variety of means. In most cases, a clinical supervisor or clinical resource nurse was approached and asked to facilitate one of the researchers attending a staff meeting to discuss the study and invite staff participation verbally and through a letter describing the study. Usually this method was effective, but sometimes repeated contact was needed to arrange a focus group. Our agency contacts always expressed interest in and support for the study, but it took time to negotiate the logistics of setting up focus groups in busy practice environments.

Three focus groups were conducted with advanced-practice nurses, 12 with other practising nurses, and four with nursing students at a local university school of nursing in the 3rd or 4th year of their baccalaureate program. Open-ended trigger questions were posed. These questions, which varied in phrasing and timing, asked the participants what they understood good (ethical) practice to be, what helped them in or constrained them from engaging in good practice, how they felt about their practice, and, finally, what their experience had been as focus-group participants. It is important to note that we introduced each focus group by setting guidelines for confidentiality and respectful participation. We also said at the outset that we were not interested in a particular theoretical approach to ethics or a "list" of particular issues. We explained that we saw ethics in terms of good practice, and wanted participants to explore that subject in whatever way was relevant for them, providing examples as needed. Our rationale for this preamble was based on our past experiences with research studies as well as with clinical and educational seminars — as soon as we began to ask about ethics, the nurses assumed we had a list of issues in mind.

The practising nurses came from a variety of settings, agencies, and units: maternity, pediatrics, medicine, surgery, critical care, emergency, operating room, oncology, psychiatry, rehabilitation, long-term care, home care, and community care. Meetings and focus groups were held on-site in a cafeteria or meeting room, or, in the case of student focus groups, a classroom. At the beginning of each focus group, the participants were asked to read/discuss the consent form regarding data collection. The participants were assured of confidentiality by the research team and were asked to respect the confidentiality of the group. Subsequently, identifiers were removed from the transcribed interviews and field notes.

All focus groups were audiotaped and transcribed and detailed field notes were taken. The investigators, joined by four graduate students in nursing (two of whom were also research assistants), met monthly to guide and facilitate the data collection and begin the analysis. Data

analysis commenced with each member reading pre-assigned transcripts and conducting a thematic analysis. Then the team met and discussed the themes, modifying them as the data were reviewed within a given transcript and across transcripts. Field notes were used to supplement this process. Gradually, relationships among themes were identified and descriptions of the findings developed. An overview of the findings was prepared for a summary paper (Varcoe et al., 2002). Further analysis was conducted by smaller teams to enhance our understanding of particular aspects of the findings, which generated other papers (e.g., Hartrick, in press; Storch, Rodney, Pauly, Brown, & Starzomski, in press), including the present one.

We will now present those findings that shed light on nurses' engagement in ethical decision-making. We will conclude by reflecting on some of the implications for nursing practice and for our understanding of ethical decision-making.

Findings

Given the exploratory nature of our study, it is not surprising that our findings were multifaceted. Overall, the practising and student nurses described ethics in their practice as both a *way of being* and a *process of enactment* (Varcoe et al., 2002). They described drawing on a wide range of sources of moral knowledge in a dynamic process of developing awareness of themselves as moral agents. Enacting moral agency involved working within a shifting moral context and working "in between" their own values and those of their employing organization, "in between" their own values and those of others, and "in between" competing values and interests. The moral identities of the participants emerged and evolved as they navigated their way through the contextual and systemic forces that shaped the moral situations of their practice (Hartrick, in press). We also learned about practice realities that created a climate for moral distress, and the ways in which nurses attempted to maintain their moral agency (Storch et al., in press).

Our findings include insights that are significant for an understanding of ethical decision-making. What was most striking about the nurses' engagement in ethical decision-making was the processual and contingent nature of their decisions and subsequent action. Their decisions and actions evolved over time and were not always in a straight line. We therefore concluded that a nautical metaphor, navigation, best reflects the nurses' ethical decision-making: they were navigating towards a moral horizon, but their course was often not smooth or certain.

The Moral Horizon

In our analysis, the horizon[7] reflected a notion of "the good"[8] towards which the nurses were navigating. The horizon was not a fixed point, but a negotiated direction. Nurses' descriptions of the horizon suggested that this direction was co-created by patients, families, and teams (see Table 1) — that is, the horizon was not necessarily set as an objective, but, rather, emerged in the context of treatment and care.

Table 1 *The Moral Horizon for the Patient, Family, and Health-Care Team*

Features of the Moral Horizon
Relief of suffering
Preservation of human dignity
Fostering of choice
Physical and psychological safety
Prevention and minimization of harm
Patient and family well-being

Choosing Alternative Routes
Waiting a while
Having others act
Shifting course away from the horizon

Reaching the Horizon
Feeling you care
Being able to cope
Coming together
Feeling respected and heard
Feeling good about the decision
Being able to let go
Being heard
Creating a sense of home

Not Reaching the Horizon
Being dehumanized
Not being valued
Suffering unnecessarily
Being punished for being ill or old
Being let down
Broken up
Feeling unsafe
Feeling powerless

For example, in a focus group of nurses working in intensive care, the participants indicated that their treatment and care made sense only in relation to the patient's illness trajectory and personal background and goals, rather than in relation to just the particulars of the disease process.

The nurses' navigation was guided by different features of the horizon — each representing a moral good. The features included relief of suffering, preservation of human dignity, the fostering of choice, physical and psychological safety, the prevention and minimization of harm, and patient and family well-being. For instance, an operating room nurse said, "I've often wondered whether the patients in these situations have been adequately informed by the physician or the surgeon. I know for a fact, in a lot of cases, that they haven't been." Choice was evident in her description of the moral horizon, as were relief of suffering caused by the surgery and prevention of harm caused by unnecessary intervention. Family well-being and choice were prominent features of the horizon described by a pediatric nurse: "Part of feeling good about what we do is when the family takes control and they are empowered to be looking after this child at home."

The features of the horizon suggested by the words of these nurses were consistent across all focus groups, albeit expressed in different ways by different groups of practising and student nurses. However, it is important to note that negotiating a shared horizon was not easy. Members of the health-care team (including nurses) were often headed in different directions. Family members were also often headed in different directions, both from each other and from members of the health-care team, as recounted by a pediatric nurse:

> Not that long ago we had a premature baby who had a huge bleed in the head. [The physicians] talked about discontinuing life support. And the [mother] couldn't do it; she could not live with herself. So we cared for the child for 2 more days and the baby died on the ventilator. For the nurses, that was really hard...because they believed it should just end.

The nurses saw continuing treatment as causing suffering and threatening the dignity of the newborn, while the mother may have constructed the treatment as preserving life and family. In this example the nurses' notions of the moral horizon needed to be negotiated with the mother. This case shows that the direction of those involved in a situation was not necessarily shared.

At times the nurses chose to or were forced to take an alternative route to the horizon, such as having other team members act in their stead or waiting a while. Another pediatric nurse, for example, told the

story of supporting the mother of a brain-injured newborn who was to be discharged. The nurses and physicians tried to impress upon the mother the severity of the child's condition and the consequences of treatment. After waiting a while, the nurse realized that her initial course (providing the mother with as much hospital and home support as possible) was not what the mother actually needed — she needed to be able to do as much as possible independently for her child. At other times, nurses veered away from the horizon. This shift occurred if they judged someone as undeserving of their care, usually described in terms of "distancing" themselves or "not caring."[9] For instance, in a focus group with emergency nurses, a nurse spoke of distancing herself from patients who came in repeatedly with problems related to substance use.

The nurses constructed their success in terms of reaching the horizon or making the best progress possible. Success was defined as the patient "feeling you care," the family "being able to cope," the team "coming together," and nurses "feeling respected and heard," "feeling good about the decision," "learning to let go," and "being heard." Learning to let go, for instance, is evident in the above story of the pediatric nurse realizing that the mother of the newborn needed to make her own choices about coping at home. They also spoke of reaching the horizon in terms of "creating a home" for patients — a point emphasized in our focus groups with nurses working in long-term care and rehabilitation. Success in reaching the horizon was usually associated with satisfaction and fulfilment. One 4th-year nursing student said, "You just know it. You can see it in your patient's face, your client's family's face, whoever it is, and you can feel it inside you that you've done the right thing." And an emergency nurse affirmed, "I'd say I love my job, I still love my job."

On the other hand, some nurses spoke of not getting close to or arriving at the horizon in terms of the patient being "dehumanized," not being "valued," "suffering unnecessarily," or being "punished for being ill or old," the family being "let down" or "broken up," and nurses feeling "unsafe" or "powerless." A nurse working in intensive care expressed it this way:

> *Ethics was a frustrating issue in the sense that you would come on a shift and the decision [to withdraw treatment] had [not been] made…that seemed apparent to me should have been made, and we sustain them through the night until maybe the next day. And that seemed to be the primary sort of dilemma that I faced. Because I'm casual, I also found that I didn't have a lot of continuity in looking after the same patients, so these issues would come up…over the course of a shift…unless the patient had*

been a long-term, chronic-care patient in the unit, so I never really got to address them because we had what was required (kind of reports and rounds in the early evening) and then over the course of the night some things would become sort of questions, but, you know, we never had an opportunity then to go on [to resolve the issues].

This nurse's sense of powerlessness and her concerns about suffering and harm are evident. Such concerns about not reaching the moral horizon were echoed by nurses from widely divergent practice contexts, as shown by comments made in a focus group with community nurses:

First community nurse: *The maternity client is a very complex client because they're in need of a lot of different programs, not just [like] someone who has abdominal surgery coming out [of hospital] and they need a dressing change and they have a family and they go through home care. [A complex maternity client] in the community — they're a breast-feeding client, they're bipolar [have a mental health condition] and they have no family support.*

Second community nurse: *But nobody recognizes that. The maternity client is [supposed to be] "just a piece of cake." "Birth is normal," you know.*

Third community nurse: *It happens everywhere. Breastfeeding is [assumed to be] automatic.*

First community nurse: *I think the mental health [aspect] is really important to keep in mind too. And I think of our partners in the social services ministry and the difficulties sometimes that have been demonstrated around being able to have an appropriate plan. I can think of an occasion where we had a family whose children were apprehended…the family were not able to provide enough resources themselves to be able to care adequately…mother [maternity client] had become psychotic in hospital, and of course English is a second language, which made it…more difficult. So, what ended up happening, because the resources weren't available, those children ended up being apprehended…when what needed to happen was that family needed to be supported in order to be able to remain together… I think ethically we really failed this family. Not just community health but the whole health-care system, including the social services ministry, because what happens time and time again is that the social services ministry holds the resources, we're here saying people need the resources, and then the fight begins in terms of trying to seek out those very few resources to keep that family together for the period of time it takes to get better. And it doesn't happen in 2 days, 3 days, a week. It takes a longer period of time for some stability and for the crisis to ease. And to me that's very distressing.*

This segment reveals a great deal about the moral horizon of nurses' work. The features of the moral horizon included meaningful

choice in childbearing, the physical and psychological safety of the woman, newborn, and family, appropriate social services intervention, and the long-term well-being of the family unit. Waiting a while (an alternative route) was not an option. This nurse did not feel that she had arrived at — or even come close to — a moral horizon for the woman, her newborn, or the family. She felt that the family's unique needs were not being valued, that they were suffering unnecessarily, and that they were being let down and broken up as a family unit. In fact, the participant who related the story later said, "It's like being punished for being ill. Bottom line. You're ill, you can't cope, that's it, end of discussion."

In summary, we have used the metaphor of moral horizon to describe nurses' understanding of the good in particular practice situations — an understanding that was shared with others and developed through a process of negotiation, and that provided direction for practice.[10] This is not to say that the nurses always negotiated effectively, or that their horizon was not overly circumscribed, or that they were accurate in identifying when (if ever) they arrived. Those are questions for further research and theoretical inquiry.

Currents Affecting Navigation

Many of the insights we gained concerned the complex and pervasive influences on nurses' ability to move towards their moral horizon. Throughout our study, nurses in every practice context identified their practice as frequently constrained or facilitated by influences beyond their immediate control. We came to understand such influences as currents affecting navigation and, thus, affecting progress towards the moral horizon (see Table 2). In what follows we will articulate those currents that nurses identified as having the most profound influence on their practice.

Table 2   *Currents Affecting Navigation*
Currents Constraining Navigation Privileging of biomedicine Corporate ethos
Currents Facilitating Navigation Supportive colleagues Professional guidelines and standards Education in ethics

One current the nurses often found themselves navigating against was a privileging of biomedicine and a corporate ethos. A segment of a focus group with operating room nurses will serve to illustrate:

First OR nurse: *I don't feel that my nursing work is complete, because I don't have the time to provide the caring emotional support that I think this particular kind of patient requires. You feel like it's a race…truly, you are ruled by the clock and not by what your patients' needs are. [There is rarely] a case where you feel that you can actually do something for your patient or make a difference to them. I feel that every minute with your patient before they're put to sleep is a bonus for that patient when they wake up, everything you can do for that person. And when you have less than 2 minutes in a less than ideal, busy hallway… then it's a very unsatisfying experience, because I just know I haven't done a good job.*

Second OR nurse: *Ethically, how can I say I'm the bad guy? I'm not the bad guy. The work environment is the bad guy…I can speak to having to do 10 cataract extractions every day, and feeling as though you're working with a gun at your head. Literally, that is the emotional feeling that I have, that the surgeon is holding a gun at my head and I am under constant pressure. So, I say I am extremely dissatisfied with my job when I have to work like that. I hate it.*

These OR nurses were trying to navigate to a place where they could spend time with and support their patients through the experience of surgery. However, the privileging of biomedicine meant that the focus was on surgical procedure. The corporate ethos meant that nurses' time spent caring was not counted or planned for, and as many procedures as possible were pushed through. The corporate goal of efficiency took precedence over patient well-being, interdisciplinary team cohesion, and nurse satisfaction. Time for quality nursing care became a prized and contested commodity. No member of the research team will ever forget the comment of the OR nurse who felt as if she was practising with a gun to her head. For her, the consequences of being unable to move towards a moral horizon were more than just dissatisfaction: she felt unsafe, exhausted, and demoralized; it was almost impossible for her to make any headway against the current.

While the words of the OR nurse are particularly poignant, similar concerns were expressed in every focus group with nurses involved in direct care. For instance, in the segment with community nurses cited above, the privileging of biomedicine meant that the intersection of a mental health problem with a birth experience, inability to speak English, and poverty fell outside the scope of agency policies,[11] and the corporate ethos meant that resources were squeezed and traded off

between health and social services. Time for quality nursing care was also contested, even if not as urgently as in the operating room.

Comments from a focus group with nurses practising on a medical unit in the large urban hospital illustrate the effect of the constraining current on nurses' well-being:

> First medical unit nurse: *We're not getting anything back and…it depletes us. And it's the depletion, and the burnout and the quitting and the three-career kind of thing. How are we…going to help our nursing profession when we're not working with [adequate] staff?…Everyone's so distraught on the unit, and I find myself, I am like that, and I try to be a really positive, energetic person. At 27, I'm starting to dwindle away, thinking what am I going to do with my life? At 27. If I'm feeling that now, I don't want to be burnt out in 5 years.*

> Second medical unit nurse: *[It's difficult to find the time to] participate in things like this [focus group] and things like in-services…it's frustrating when you can't get 20 minutes to go to an in-service…because you haven't finished your charting, or because you've got your vital signs to take and because you've got a new admission coming in and you know you can't get away on the floor.*

> First medical unit nurse: *There's no administration support.*

> Second medical unit nurse: *I think that's what it is. They want you to attend them but…*

> First medical unit nurse: *…on your own time, energy, etc., etc. I find that there's not a lot of support. I don't think that they [administration] don't want to give it, I don't think they have the availability to give it to us.*

The workload on the acute-care medical unit where these nurses practised was increasingly demanding, and resources to support staff (such as in-services) were described as largely unavailable or inaccessible. The above statement "I don't think they have the availability to give it to us" suggests that the corporate ethos was controlled at a level beyond first-line management. In the province where our study was conducted, the provincial government distributed funds to regional boards, which then made allocation decisions.[12]

Fortunately, there were also situations in which the prevailing currents facilitated nurses' attempts to navigate towards a moral horizon. Supportive colleagues in nursing and other disciplines were a major influence. One nurse practising on a maternity unit put it this way:

> *For me a problem shared is a problem halved. I have shared it and [got] someone else's perspective on it, and maybe it wasn't really that*

huge a deal. When someone else's perspective comes to it...all of a sudden it isn't such a huge problem any more — "gee, it's not just me that felt this way, it's a more common feeling than I realized." I guess it gives me permission to have felt that way, knowing that other people have the same issues. It just cuts it down inside.

Likewise, in a focus group with emergency nurses, the participants spoke of situations in which interdisciplinary team work generated mutual respect with their medical colleagues. In fact, when we asked participants in all of the focus groups what helped them to deal with ethical problems in their practice, the consensus was "supportive colleagues."[13]

Nurses in advanced-practice and management positions told of numerous initiatives they had taken to improve the moral climate of the workplace. These initiative included a focus on interdisciplinary team work, the establishment of accessible practice guidelines and policies, and education in ethics, all three of which were affirmed by other practising nurses as improving the moral conditions of their work (Storch et al., in press). An advanced-practice nurse explained:

I think...of the patient consults that I get involved in, there's always a huge element of ethics involved, and many times the reason why I'm there is because there's some sort of breakdown in the system and there's a perception that there's a gap in service...so the whole notion of being an advocate for patients [is part of it]...promoting the team unity and collegial relationships...fostering and maintaining those relationships but at the same time recognizing what is happening with the patient, that things are not going the way they should...that can be quite stressful at times...and it really involves a lot of courage and sometimes standing up and being the voice calling out in the wilderness with not a lot of backup until you manage to convince people to go along with you.

The actions of this advanced-practice nurse no doubt helped the nurses and other team members to move towards their moral horizon. Dealing with "gaps" in service and "being an advocate for patients" would do much to counteract the privileging of biomedicine and the corporate ethos. By "fostering and maintaining those relationships," this nurse was helping colleagues to be mutually supportive, "recognizing...that things are not going the way they should" indicates that she was attentive to professional standards and guidelines, and managing to "convince people to go along with you" certainly reveals at least some informal education in ethics. While this is the story of just one advanced-practice nurse, it is reflective of what we heard from her colleagues in nursing leadership positions (Storch et al., in press).

Implications for Practice

The findings from our study shed some light on the process of ethical decision-making and nurses' experiences in terms of their ethical decisions and the role of ethics in their practice environments. We have used a nautical navigation metaphor to describe the processual and contingent nature of the nurses' experiences. The notion of a moral horizon reflects "the good" towards which the nurses were navigating. The horizon was not a fixed point but, rather, a direction negotiated by patients, families, and teams. Currents within the moral climate of nurses' work significantly influenced their progress. All too often, nurses found themselves navigating against a current characterized by the privileging of biomedicine and a corporate ethos.[14] Fortunately, supportive colleagues as well as professional standards and guidelines and ethics education constituted strong currents, helping nurses to move towards the horizon.

We emphasize, though, that the nurses in this study, as moral agents, often experienced a great deal of difficulty navigating. One nurse working in long-term care said: "Not being able to make decisions is like atrophy of a muscle. I can hardly remember being in control of nursing practice, of my ethics, of making these decisions — it's eroding." People in nursing and other health-care professions, health-care ethics, and health policy need to take such comments seriously. We have argued elsewhere that strengthening nurses' moral agency means attending to nurses' personal needs while at the same time improving the moral climate of their practice (Hartrick, in press; Rodney, 1997; Rodney & Varcoe, 2001; Starzomksi, 1997, 1998; Storch, 1999; Storch et al., in press; Varcoe et al., 2002; Varcoe & Rodney, 2002). While there is some research identifying and implementing positive workplace initiatives,[15] much more is needed. In the meanwhile, we will highlight some of the practice implications of the present findings.

It is not surprising to find that the currents constraining the nurses' moral agency were so pervasive. Today's practice environments pose myriad ethical challenges, including increasing complexity of patient, family, and community needs, escalating biotechnological advances, a rightward shift in socio-political climate, and increasingly stressed nursing workplaces (Adams & Bond, 2000; Aiken, Clarke, & Sloane, 2000; Barry-Walker, 2000; Canadian Nurses Association, 1998a; Duncan et al., 2001; Health Canada Office of Nursing Policy, 2001; Mohr, 1997; Nagle, 1999; Oberle & Tenove, 2000; Redman & Fry, 2000; Rodney & Varcoe, 2001; Varcoe, 2001; Varcoe & Rodney, 2002). While we do not claim to have identified an exhaustive list of currents, we believe that

those we have identified are salient ones. Understanding how such currents affect nurses' progress towards a moral horizon provides a foundation from which to improve the moral climate of nursing practice.

One improvement we can make is to *enhance the quality of the relationships* between nurses, other health-care providers, patients, and families. The interpersonal context in which ethical decisions are made is profiled in our study. Negotiating a shared horizon was often difficult, requiring effective communication among all the various parties involved. Further, the current created by the privileging of biomedicine and the corporate ethos disrupted interdisciplinary team functioning. This is evident in the OR nurse's comment that she felt as if she was practising with a gun to her head — a gun held by the surgeon but put there by an organizational mandate to process as many patients as possible. Conversely, positive relationships with colleagues in nursing and other disciplines have tremendous potential to help nurses stay on course. While there is growing attention in the health-care and ethics literature to the role of trust in resolving end-of-life issues (Burgess, Rodney, Coward, Ratanakul, & Suwonnakote, 1999; Kuhl & Wilensky, 1999; Rodney, 1994, 1997; Solomon et al., 1993; Starzomski, 1997, 1998; Taylor, 1995; Tilden, Tolle, Nelson, Thompson, & Eggman, 1999), not enough has been written about the role of trust in day-to-day processes.[16] We need to better articulate — and subsequently defend — the day-to-day relational processes that influence the moral climate of nursing practice and interdisciplinary team functioning (Bergum, 1993, 1994; Gadow, 1999; Hartrick, 2002; Jameton, 1990; Liaschenko, 1993b; Liaschenko & Fisher, 1999; Sherwin, 1998).

Secondly, we can help nurses to *use the language of ethics in a way that supports their practice*. Throughout the focus groups, nurses told us that their voices were seldom heard as they confronted everyday as well as quandary ethical problems. To some extent, they were not heard because they tended not to explicitly flag a problem as ethical. While all of the nurses spoke about good practice, most did not consciously speak of it in terms of ethics. For instance, a maternity nurse referred to the embeddedness of ethical decisions in her practice:

> *You make so many decisions, it sort of comes from the heart…almost automatically…I don't think we can, it would be very difficult to just try and label…to try and figure this was an ethical decision, this was a decision that was totally governed by my profession or my obligation to the situation. I'm not sure that I can verbalize [it].*

Their failure to use ethical language is no indication that the nurses were not making ethical decisions or practising ethically. Indeed, as is

indicated by our horizon metaphor, they were almost always aware of (though not necessarily following) a value-based direction in their practice. A number of participants spoke of formal education in ethics having helped them to find their voice. Thus, one of the implications of our research is the need for more formal and informal nursing education in ethics (Storch et al., in press). Such education ought to attend to the relational context of nursing practice and everyday as well as quandary ethical problems.

Thirdly, we need *to improve the moral foundations of health policy*. In our study, health policy influenced the nurses' ability to work towards a moral horizon at every level of practice — from staffing decisions to resuscitation guidelines to discharge criteria to relationships between government departments. We need nursing expertise and nursing leadership to analyze the moral foundations of health policy (Malone, 1999; Mitchell, 2001; Storch et al., in press). And we need to involve nurses at every level of practice in re-shaping health policy so that it is more supportive of the ethical practice of nurses and other health-care providers.

We realize that our recommendations for improved practice will not be easy to implement. In the words of an advanced-practice nurse cited earlier, it will also take courage on the part of individuals and groups (Storch et al., in press). However, as one intensive-care nurse said:

> Well, we have to have some hope. And so that's how I look at it. …I am in no way thinking that there's not more work to be done. There definitely is. But I have seen successes, and so I think it is possible. But we need to engage everybody…it has to be a level playing field. So people have to have — all people, physicians, nurses…and our health-care team — …basically the same values and mission, really, about what we're trying to do.

Nursing has tremendous capacity to make a difference, to move towards moral horizons for the benefit of patients, families, and communities.

Reflection: Ethical Theory and Ethical Decision-Making

We will close by reflecting back on theory and practice in health-care ethics. Our findings show that ethical decision-making is much more than the rational, objective application of ethical principles that traditional ethical theory implies. Traditionally, ethical problems in health care have been seen to collapse into dichotomous (yes/no) questions about what a moral agent (usually a lone physician) should do with a

patient, usually in a life-or-death situation. The answers have been seen as residing in the application of foundational ethical principles — autonomy, beneficence, nonmaleficence, and justice (Beauchamp & Childress, 1989). It is assumed that an objective, rational, analytic process will furnish a concrete and correct answer, outside the familial, social, cultural, and political context of the problem (Baylis, Downie, Freedman, Hoffmaster, & Sherwin, 1995; Burgess et al., 1999; Churchill, 1997; Evans, 2000; Fox, 1990; Gadow, 1999; Hoffmaster, 1990, 1999; McDonald, 1999; Stephenson, 1999; Weisz, 1990; Yeo, 1994).[17] At the same time, much of the early nursing research on ethical decision-making was based on theories of moral reasoning, applying principles of justice and/or care to hypothetical situations (Cameron, 1991; Cassidy, 1991; Cooper, 1991; Fry, 1987; Georges & Grypdonck, 2002; Ketefian, 1989; Munhall, 1983; Omery, 1983; Penticuff, 1991; Rodney, 1997). The participants in our study, in contrast, portrayed decision-making as processual and highly contextual. Decisions were gradual and constituted a journey towards a mutually constructed and pluralistic moral horizon. This finding is consistent with those of other nursing studies. When studies began to move from hypothetical situations to accounts of *practice,* ethical decision-making came to be seen as more nuanced and contextual (Benner, Tanner, & Chesla, 1996; Chambliss, 1996; Fry, 1999; Gaul, 1995; Georges & Grypdonck; Rafael, 1996; Redman & Fry, 2000; Rodney, 1997; Sherblom, Shipps, & Sherblom, 1993). Our findings thus support those of nursing studies on moral reasoning and ethical decision-making that emphasize context and action.

Nursing research on ethical decision-making that emphasizes context and action parallels current theoretical shifts in health-care ethics. These shifts entail a proliferation of alternatives to principlism, and include (but are not limited to) a revival of casuistry, the call for an inductivism based on empirical information or ethnography, interest in narrative bioethics, the articulation of care-based ethics, and relational ethics (Wolf, 1994, p. 400; see also Bergum, Boyle, Briggs, & Dossetor, 1993; Churchill, 1997; Gadow, 1999; Hoffmaster, 1999; Levi, 1996; Omery, 1983; Starzomski, 1997; Yeo, 1994).[18] Each of these alternative approaches to ethical theory can be considered a form of *contextualism.* Contextualism takes into account the reciprocity of facts and values: "moral problems must be resolved within concrete circumstances, in all their interpretive complexity, by appeal to relevant historical and cultural traditions, with reference to critical institutional and professional norms and virtues" (Winkler, 1993, p. 344). In other words, contextualism transcends the reductionist tendency of principle-based ethics by

focusing on particular people and particular relationships in particular contexts.

The rise of contextual ethics has been associated with approaches to ethical decision-making that are more sensitive to context (see, for instance, Jonsen, Sieglar, & Winslade, 1986; Keatings & Smith, 2000, pp. 42–43; Kuhl & Wilensky, 1999; McDonald, 2002). Theorists and health-care providers who use a contextual approach to ethical decision-making aim for a "philosophical understanding of the fundamental concepts used in moral analysis and the tensions between them" in order to "sort out confusions, clarify disagreements, and promote creative problem-solving" (Yeo, 1996). Contextual ethical theory therefore corresponds with models of ethical decision-making that are more attentive to the real world of clinical practice. Such models can be used to help nurses to participate with patients, families, and other providers in working towards a moral horizon. For example, McDonald's model provides guidelines for a group to move towards conflict resolution and consensus.

Further, insights from nursing research can help to shape the evolution of ethical decision-making models. Nurses, other members of the health-care team, and patients and families are engaged in multiple decisions as they work their way towards a horizon. Not all of the decisions are life-and-death (Benner, Tanner, & Chesla, 1996; Canadian Nurses Association, 1998b; Chambliss, 1996). In the account by the pediatric nurse cited earlier, for instance, the mother taking her seriously ill newborn home had made some initial decisions about life-saving treatment (a quandary problem); subsequent decisions about support at home (everyday problems) would follow, and would take time. Current models and frameworks are not sufficient. We need more research into decision-making approaches that will address the interface of everyday and quandary ethical problems and their evolution (Rodney, 1997; Storch, Rodney, & Starzomski, 2002). Nurses are in a good position to contribute to such research.

Notes

1. The terms biomedical ethics, bioethics, and medical ethics are often used to refer to ethical differences between health-care providers (usually physicians) and patients. Our preferred term is health-care ethics, as it encompasses ethical concerns related to providers, patients, families, communities, health organizations, and society as well as biomedicine — all of which are relevant for nursing.
2. Ethics is a branch of philosophy that focuses on questions of right/wrong, value or disvalue. The widespread application of ethical theory to health care is a recent phenomenon. The term bioethics first appeared about 30 years ago with the publication

of a text on biological knowledge and human values (Roy, Williams, & Dickens, 1994, pp. 3–4; see also Jonsen, 1997; Pellegrino, 1997; Storch, Rodney, & Starzomski, 2002) and came to represent academic and professional efforts to address ethical issues posed by developments in the biological sciences (Roy et al., p. 4). With roots in medical ethics, philosophical ethics, and religious ethics, bioethics flourished and diversified as a result of rapid advances in medical science and technology and societal changes (Evans, 2000; Fox, 1990; Jonsen; Pellegrino; Roy et al., pp. 4–13).

3. Ethical decision-making has traditionally been thought of as a structured form of moral deliberation. Moral deliberation occurs when a moral agent confronts an ethical problem and asks the question "What ought I to do?" (Beyerstein, 1993, p. 422).

4. Traditional perspectives on moral agency reflect a notion of individuals engaging in self-determining value-based choice (Sherwin, 1992; Taylor, 1992). Newer perspectives see moral agency as enacted through relationships in particular contexts (Mann, 1994; Rodney, 1997; Sherwin, 1992, 1998; Taylor, 1992). For discussions of moral agency in nursing, see Benner (2000), Georges and Grypdonck (2002), Jacobs (2001), Raines (1994), and Varcoe and Rodney (2002).

5. "The Ethics of Practice: Context and Curricular Implications for Nursing." Principal Investigator J. Storch; Co-Investigators G. Hartrick, P. Rodney, R. Starzomski, & C. Varcoe (July 1999). Funded by Associated Medical Services Inc. (Bioethics Division) and internal University of Victoria Social Sciences and Humanities Research Council grants.

6. For other findings, see Hartrick (in press), Storch et al. (in press), and Varcoe et al. (2002).

7. Our notion of moral horizon is informed by Bernstein (1991) and Taylor (1992). Bernstein speaks of a moral horizon as a moral point of view, while Taylor speaks of negotiating a value-based direction.

8. Our understanding of this term is influenced by Patricia Benner and her colleagues, who build on Aristotle's work. We understand ethics in terms of *good practice* — practice that comes from good character and good action (Aristotle, c. 320 BC/1985; Benner et al., 1996). In other words, "one's acts are governed by concern for doing good in particular circumstances, where being in relationship and discerning particular human concerns are at stake and guide action" (Benner, 2000, p. 5). In nursing, we use various principles or concepts to help us to articulate ethical goods (e.g., autonomy, beneficence/nonmaleficence, justice, fidelity, care); importantly, ethics is part of our daily work, not just in life-and-death situations. "Even in clinical situations, where the ends are not in question, there is an underlying moral dimension: the fundamental disposition of the nurse toward what is good and right and action toward what the nurse recognizes or believes to be the best good in a particular situation" (Benner et al., p. 6).

9. For discussions of deservedness, see Rodney and Varcoe (2001), Varcoe (1997, 2001), and Varcoe and Rodney (2002).

10. Sally Gadow (1999) calls this type of negotiation a "relational narrative": "Ethical narratives created by patient and nurse from the homeland of their engagement are...more than individual accounts: they are relational narratives" (p. 65).

11. Cassidy, Lord, and Mandell (1995) offer an insightful analysis of intersectionality and oppression.

12. See Brown (1996) for an interesting analysis of the power relationships between provinces and regional boards.

13. See Rodney (1997) for similar findings from an ethnography conducted on two acute-care medical units.

14. See Rodney and Varcoe (2001), Varcoe (2001), and Varcoe and Rodney (2002) for similar findings from ethnographies conducted in two acute-care medical units and two emergency units.

15. See Laschinger, Finegan, Shamian, and Casier (2000) for an insightful research study on the effects of organizational trust and empowerment in restructured health-care settings on staff nurse commitment. See also Aroskar (1995), Corley and Goren (1998), Jameton (1990), McDaniel (1998), and Olson (1998) regarding strengthening nursing as a moral community.

16. For a notable exception, see Peters and Morgan's (2001) exploration of trust in a home-care context.

17. Such criticisms of principle-oriented ethics sometimes have more to do with how the principles have been traditionally used in health-care ethics than with a weakness in the principles themselves (Churchill, 1997; Rodney, 1997). The principles have been somewhat unfairly caricatured (Levi, 1996; Wolf, 1994; Yeo, 1994). Beauchamp and Childress (1989) make it clear that they view principles in terms of what they call "composite theory" (p. 51). They explain that "each basic principle [has] weight without assigning a priority weighting or ranking. Which principle overrides in a case of conflict will depend on the particular context, which always has unique features" (p. 51). In other words (and contrary to what many critics imply), the principles are "binding but not absolutely binding" (p. 51). The principles can thus be viewed as useful heuristic devices (Stevenson, 1987) rather than as rigid prescriptions.

18. Casuistry is an inductive approach to ethics that proceeds through case analyses (Arras, 1991; Jonsen, 1995; Jonsen & Toulmin, 1988; Levi, 1996; Toulmin, 1981). Inductivism is a more general term referring to the use of qualitative and quantitative data to inform ethical theorizing (Hoffmaster, 1991, 1993; Jameton & Fowler, 1989). Narrative bioethics has emerged as the use of story to inform ethical practice (Frank, 2001; Nisker, 2001). The primary focus in care-based ethics is relationships and care (Flanagan, 1991; Gilligan, 1982; Sherwin, 1992), while in relational ethics it is human meaning and connectedness (Bergum et al., 1993; Sherwin, 1998).

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Evaluation of an Integrated Model of Discharge Planning: Achieving Quality Discharges in an Efficient and Ethical Way

Donna L. Wells, Chantale M. LeClerc, Dorothy Craig, Douglas K. Martin, and Victor W. Marshall

Dans un contexte où les séjours hospitaliers sont écourtés, la planification des congés est une question qui prend de plus en plus d'importance. Selon les études, les pratiques en matière de congés comportent des difficultés à l'échelle des ressources et des problèmes d'ordre déontologique. Cette évaluation d'un modèle intégré de planification de congés (*integrated model of discharge planning – IMDP*) inclut une évaluation de l'utilisation des ressources, du respect envers les personnes dans la prise de décisions et de la capacité du modèle à répondre aux besoins des patients âgés, des familles et des professionnels. Deux études de cas portant sur un hôpital universitaire et un hôpital communautaire ont été mises à contribution pour illustrer le contexte dans lequel la planification de congés a été appliquée. Des analyses comparatives de cas et du processus même de planification des congés appliqué auprès de 48 patients indiquaient que l'IMDP était viable et que les patients étaient satisfaits. De plus, les ressources hospitalières ont été utilisées de façon efficace et les patients ont pu participer à la prise de décisions. L'étude fait état de la réussite d'une approche prometteuse en matière de planification des congés.

Discharge planning has become increasingly important in an era of shortened lengths of stay in hospital. Prior research demonstrated that discharge practices presented resource and ethical problems. This evaluation of an integrated model of discharge planning (IMDP) included an assessment of resource utilization, respect for persons during decision-making, and the impact of the model in meeting the needs of elderly patients, families, and professionals. Two case studies involving a university and a community hospital were used to illustrate the context in which discharge planning occurs. Within and cross-case analyses of the discharge-planning process for 48 patients indicated that it is possible to implement the IMDP and that participants were satisfied. Further, hospital resources were used efficiently and patients were involved in decision-making. The study represents a successful implementation of a promising approach to discharge planning.

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Discharge planning continues to be a critical issue in clinical practice and hospital administration. The challenge lies in achieving timely discharge while maintaining high-quality care in an ethical way. In response to a decade or so of budgetary cutbacks and large-scale restructuring, patient lengths of stay in Canadian hospitals have been drastically reduced. Data from the Canadian Institute for Health Information (2000) indicate that the average length of hospital stay in Canada dropped by more than 5% between 1994–95 and 1997–98, from 7.4 days to 7 days. Elderly patients have been the target of approaches aimed at earlier discharge, because they are the highest users of hospital services (34.7% of all hospitalizations in 1997–98) and because their lengths of stay are nearly double those of patients in other age groups (10.5 days vs. 5.4 days). Yet studies have shown that such discharge-planning practices raise pragmatic issues with regard to efficiency and are ethically questionable in that they can be disrespectful to elderly patients, families, and health professionals (Dill, 1995; Grimmer, Moss, & Gill, 2000; McWilliam, 1992; McWilliam & Sangster, 1994; Wells, 1997). Issues of inefficiency include misuse of the time and energy of professionals during the discharge-planning process, because their involvement is not carefully linked with the clinical trajectory of patients (Wells, 1997).

Lack of respect for patients and families in the discharge-planning process is related to the absence of involvement in the decision-making process (Dill, 1995; Grimmer et al., 2000; McWilliam, 1992; McWilliam & Sangster, 1994; Wells, 1997). The moral or ethical principles at stake here are informed decision-making and patient autonomy. As well, because of the hospital's emphasis on shortened stays, professionals have reported that sometimes they discharged patients before they felt that patients were medically ready (Wells, 1997). The ethical conflict for professionals resided in their conflicting loyalties: they had to choose between meeting the demands of the organization and providing quality patient care. When planning takes place too early and does not include the involvement of patients and families, discrepancies are reported between the needs identified and planned for in hospital and the actual needs of patients once they return home (Armitage & Kavanagh, 1997; Bull & Kane, 1996; Cummings, 1999; LeClerc, Wells, Craig, & Wilson, 2002; McBride, 1995; Mistiaen, Duijnhouwer, Wijkel, de Bont, & Veeger, 1997; Perlman Simon, Showers, Blumenfield, Holden, & Wu, 1995; Prescott, Soeken, & Griggs, 1995; Proctor, Morrow-Howell, & Kaplan, 1996; Storer Brown, 1995).

In order to address these identified problems, several approaches to discharge planning for elderly persons have been developed and
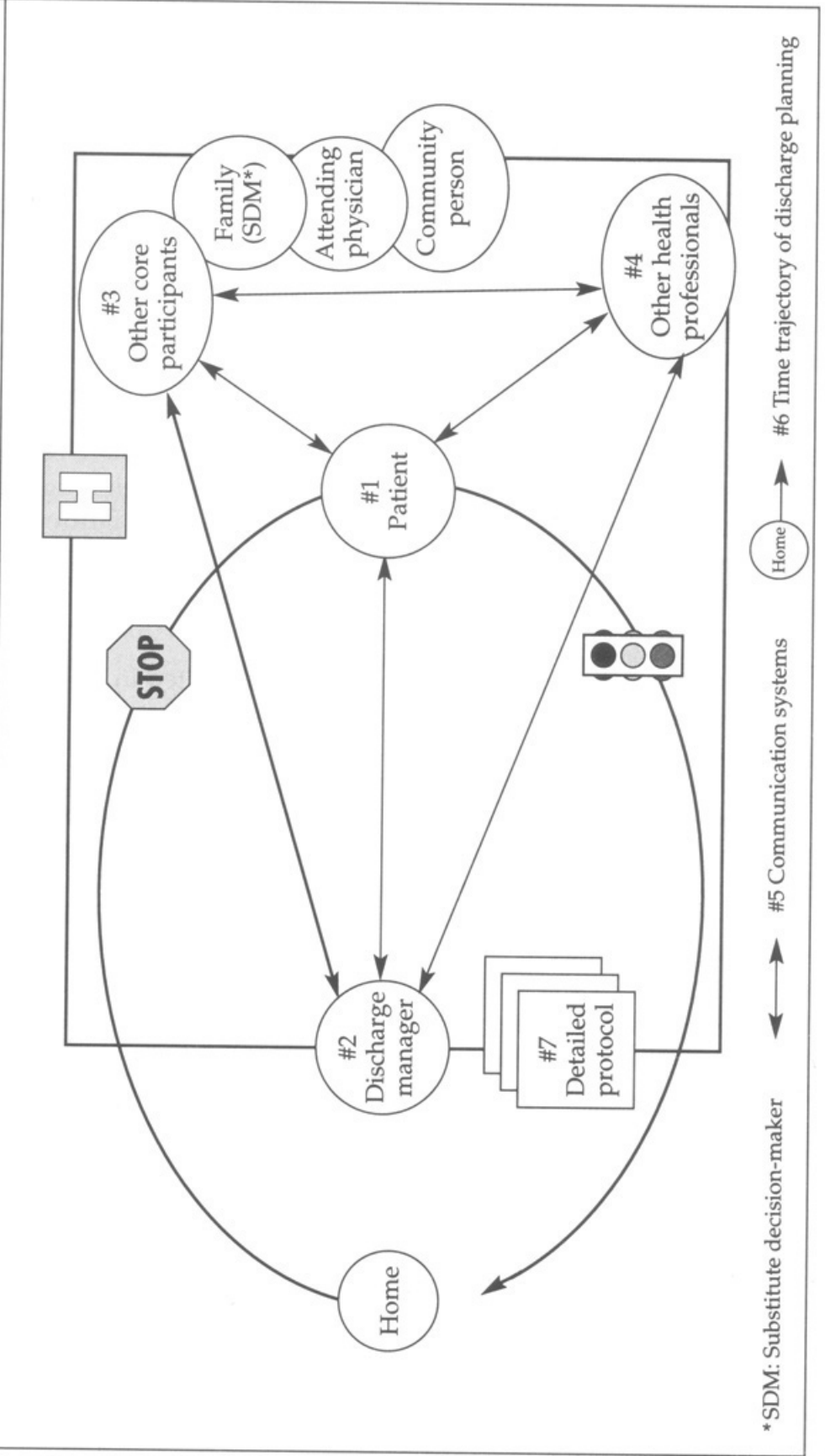
evaluated using a variety of designs, including five randomized controlled trials (Evans & Hendricks, 1993; Naughton, Moran, Feinglass, Falconer, & Williams, 1994; Naylor et al., 1994, 1999; Weinberger, Oddone, & Henderson, 1996) and two quasi-experimental projects (Bull, Hansen, & Gross, 2000; Haddock, 1994). These intervention studies, which involved a discharge planner or equivalent who had explicit responsibility for planning and which used an assessment and/or protocol, indicated such positive organizational outcomes as: increased numbers of patients discharged home (Evans & Henricks); fewer re-admissions (Evans & Hendricks; Haddock; Naylor et al., 1994, 1999); fewer total days rehospitalized (Bull et al., 2000; Naylor et al., 1999); and lower total acute-care hospital costs (Naughton et al.; Naylor et al., 1999). In addition, these interventions resulted in increased patient and family satisfaction related to, for example, more continuity of information regarding managed care (Bull et al.; Weinberger et al.) and fewer unmet treatment needs post-discharge (Haddock). The reported findings regarding total length of stay are equivocal (Evans & Hendricks; Haddock; Naughton et al.; Naylor et al., 1999; Weinberger et al.).

These discharge-planning approaches are limited in that they lack an explicit theoretical underpinning. As well, the authors do not describe the rationale for their selected interventions. Furthermore, the research does not explicitly identify the importance of addressing issues of efficiency as well as moral and ethical issues related to informed decision-making and patient/family and professional autonomy. Moreover, none of the studies was conducted in Canada.

The Integrated Model of Discharge Planning

To address the shortcomings of existing approaches, the Integrated Model of Discharge Planning (IMDP) was developed. This model evolved from a study with 130 professionals, patients, and families who were asked in focus groups or interviews to describe an ideal approach to discharge planning (Wells, Martin, Moorhouse, Craig, & Foley, 1999). The IMDP (Figure 1) consists of seven principles that together constitute an integrated approach to discharge planning, namely: (1) the patient is at the centre of the process; (2) a single person manages the planning; (3) the patient, family, discharge manager, physician, and a community person are the key participants; (4) other health professionals are involved only as the need arises; (5) communication is open and oriented to mutual agreement; (6) discharge planning is directly linked to the patient's clinical and social circumstances; and (7) planning is

Figure 1 *Integrated Model of Discharge Planning for Acutely Ill Elderly Patients*

#3 Other core participants

Family (SDM*)

Attending physician

Community person

#4 Other health professionals

#1 Patient

#2 Discharge manager

#7 Detailed protocol

STOP

Home

Home

#5 Communication systems

#6 Time trajectory of discharge planning

*SDM: Substitute decision-maker

guided by a practice protocol comprising 24 activities (see Appendix 1). Participants in this study believed that this integrated approach would be resource-efficient and facilitate high-quality discharge care. In 1997 a pilot project was undertaken to examine the feasibility of implementing the empirically derived IMDP in the hospital setting (LeClerc & Wells, 2001). Findings revealed that the IMDP could be operationalized in practice.

Jurgen Habermas's (1984, 1987) critical theory, detailed elsewhere (Wells, 1995, 1997), also underpinned the design of the IMDP. Specifically, the theory offered a rationale for the need to balance imperatives related to the pragmatic issues of efficiency and moral or ethical issues related to professional and patient autonomy in the discharge-planning process. In accordance with Habermas's communicative action perspective, the reasons behind particular discharge-planning activities, the purposes or ends to be achieved, and the motives of participants were open for discussion by all those involved. This reflective process could, it was believed, foster greater accountability in, and lend legitimacy to, discharge planning, as participants would be responsible for coming to an agreement on the adequacies of particular decisions. Habermas's concept of discourse ethics was applied to the IMDP as a procedural guide to communicative action in discharge planning, which involves the application of discursive rules (i.e., the commitment to truth or accuracy; sincerity or being true to your words, taking conflicting values into account; and comprehensiveness or completeness of the information leading to decisions) to communication. In the present study, discursive rules in the discharge planning of elderly patients included: considering the opinions of participants, engaging appropriate people at the right time, and ensuring the adequacy of information used in decision-making.

Purpose of Study

The purpose of the present study was to evaluate the process and impact of the IMDP in: (a) achieving the hospital's goals concerning the efficient use of resources given fiscal constraints; and (b) facilitating high-quality discharge planning that meets the needs of elderly patients, their families, and health professionals. The primary objective of the process evaluation was to determine whether all of the relevant activities of the discharge-planning protocol were implemented as planned and within the predetermined time frames. Also, we assessed the barriers and facilitators to implementation and assessed whether there was a workable plan at discharge. As well, we evaluated the

effects or outcomes of using the IMDP in terms of (a) resource use, and (b) respect for persons. The research questions related to resource use were: How much time is required for the core participants to plan for discharge? What is the length of involvement for other professionals? What are patient outcomes related to use of health-care resources/services (e.g., length of stay in hospital, re-admission, and unanticipated events)? The research questions related to respect for persons were: What is the relative involvement of core participants? Are patients, families, and discharge managers satisfied with the discharge-planning process and the final plans that are made? Are there any disagreements between core participants concerning the discharge-planning process and the final plans that are made, and are these resolved? Is the final discharge plan adequate post-discharge? Are patients and families provided with information and instruction about the discharge services to be provided, the patient's medical/health condition, and related treatments?

Research Design and Methods

Design

A program evaluation approach (Patton, 1997) was used to determine (a) whether the activities of the IMDP could be implemented in two different hospital settings, and (b) the related use of resources and whether respect for persons could be demonstrated.

A case study design constituted the specific research approach, which permitted an in-depth investigation of a phenomenon (i.e., discharge planning using the IMDP) within context (i.e., hospital medical units) (Ragin, 1987; Yin, 1994). The units of analysis were: the IMDP implemented on two general medical units, the patients and their family members who participated in the evaluation of the IMDP, and the discharge managers who implemented the IMDP.

Sample

Two sites were purposively selected for the evaluation: one university acute-care hospital and one community acute-care hospital in the metropolitan Toronto area of the province of Ontario. Two discharge managers, one from each hospital, were purposively selected to implement the IMDP. They used the model to guide discharge planning and completed all relevant forms for all patients who met the following criteria during the study period: admitted to a general medical unit, aged 65 years or over, not awaiting placement in a long-term-care facility,

acutely ill and expected to be discharged home, agreeable to participation in a telephone interview, and no diagnosis of dementia. Every third completed patient case was selected for evaluation. This method was chosen to ensure that (a) the discharge managers would remain blind to patient cases subjected to analysis, and (b) the desired sample would be obtained within the study time frame based on anticipated number of admissions to the study sites. A sample of 25 patient cases was obtained from the university hospital and 23 patient cases from the community hospital.

Data Collection

Following ethical approval by the Office of Research Services at the University of Toronto and the ethical review boards of both participating hospitals, data collection took place over a 9-month period between April 1999 and January 2000. A research assistant hired for the study trained the two discharge managers in how to use the IMDP and its related protocol, and how to complete all data-collection forms, which included: One Stop Client Access Assessment form (OSCA) (Haliburton-Kawartha-Pine Ridge District Health Council, 1991); the record of meetings/contacts form; and the initial, updated, and final discharge plans. With the exception of the OSCA, all of these forms were developed for the study and tested in a pilot study (LeClerc, 1998; LeClerc & Wells, 2001).

As well, structured telephone interviews were conducted 6 weeks post-discharge with 16 patients and three family members from the university hospital and 18 patients and five family members from the community hospital. Despite numerous attempts, we were unable to reach the remaining subjects by telephone. Patients and their family members provided verbal consent to be telephoned by the research assistant for interview purposes. The structured interviews were focused on patients' and families' satisfaction with the discharge-planning process and the final discharge plans, their level of involvement in planning, the adequacy of final plans, and any unanticipated events. The interviews lasted 30 minutes and were hand recorded as close to verbatim as possible.

Face-to-face structured interviews were conducted with the two discharge managers. These interviews were concentrated on the discharge manager's perceptions of the IMDP and the facilitators and barriers to its implementation. With the verbal consent of the discharge managers, these interviews were audiotaped and transcribed for data analysis.

Data Analysis

Descriptive statistics were used to describe the sample of patients and the outcomes related to the process and resources expended in using the IMDP. Analysis involved within- and across-case comparisons at each hospital using the logic of comparative case analysis described by Marshall (1997) and Ragin (1987). Following this logic, similarities and differences are identified within and across cases (on the same analytic issues or research questions) in order to establish patterns and draw conclusions about the cases under investigation.

Results

Demography of the Sites, Discharge Managers, and Patient Sample

Table 1 summarizes the demographic characteristics of the sites, discharge managers, and patient sample. The university hospital, an acute-care facility located in downtown Toronto, was a mid-sized medical complex with 277 beds. The general medical unit on which the IMDP was evaluated comprised 32 beds. The discharge planner who implemented the discharge-planning protocol at this site was a full-time, master's-prepared social worker with 19 years of post-degree experience in a hospital setting. The 25 patients who participated in the evaluation ranged in age from 66 to 89, with an average age of 79.2. Forty percent of patients were female, 28% were non-English-speaking, 32% were married, and 52% lived alone. Stroke (20%), congestive heart failure (12%), and chronic obstructive pulmonary disease (COPD) (8%) were the three most frequently occurring admission diagnoses. Patients had an average of 2.7 co-morbidities. The average length of hospital stay was 13.9 days. At discharge, 68% of these patients returned to their homes.

The community hospital, an acute-care facility located in a Toronto suburb, was a large complex with 553 beds. The evaluation was conducted on a 30-bed medical unit. The discharge planner who implemented the IMDP at this site was a full-time, college diploma-prepared registered nurse with 22 years of hospital experience, 19 of which were at this site. The 23 patients who participated in the evaluation ranged in age from 66 to 96 with an average age of 78.1. Fifty-two percent of patients were female, 8.7% were non-English-speaking, 47.8% were married, and 39.1% lived alone. Pneumonia (13%), renal failure (13%), and COPD (8.7%) were the three most frequently occurring admission diagnoses. Patients had an average of 0.8 co-morbidities. The average length of hospital stay was 7.2 days. At discharge, 95.7% of these patients returned to their homes.

Table 1 *Demographic Characteristics of Patients, Discharge Managers, and Hospital Sites*

		University Hospital	Community Hospital
Patients	Sample size	$n = 25$	$n = 23$
	Age (years)	66–89 (X = 79.2)	66–96 (X = 78.1)
	Gender	40.0% women, 60.0% men	52.0% women, 48.0% men
	Linguistic background	28.0% non-English-speaking 72.0% English-speaking	8.7% non-English-speaking 91.3% English-speaking
	Living arrangements	52.0% live alone 28.0% live with spouse 20.0% live with other relative	39.1% live alone 30.4% live with spouse 30.5% live with other relative
	Diagnoses (top 3)	20.0% CVA 12.0% CHF 8.0% COPD (60.0% various diagnoses)	13.0% pneumonia 13.0% ESRF 8.7% COPD (65.3% various diagnoses)
	Co-morbidities (number)	2.7	0.8
Discharge managers	Education	master's in social work	diploma in nursing
	Job status	full-time	full-time
	Experience (years)	19	22
Hospital sites	Total beds in facility	277	553
	Total beds on case unit	32	30
	Type of unit	medicine	medicine

Process Evaluation

In both case studies, all discharge-planning protocol activities were implemented. However, some of these were not completed as fully as others or within the predetermined time frames. Specifically, the least consistently implemented activity was involving a relevant community person (including homemakers, home-care liaison workers, hospital-based staff from a regional geriatric program, and staff from rehabilitation facilities) and the attending physician as core participants. One discharge manager explained that "if we had to involve outside resources…depending on what their schedules and case loads were like, that could cause delays just because they couldn't get down to us right away." The other said, "Physicians do not like to participate too early in the discharge-planning process."

Although the initial assessment using the OSCA was completed for 100% of patients at both hospitals, it was not completed within 3 days of admission for 64% of patients at the university hospital and 30.4% of patients at the community hospital (see Table 2). The higher percentage of delayed completions at the university hospital can be accounted for by the complexity of those patients' medical conditions. They had an average of 2.7 co-morbidities, as compared to 0.8 for patients at the community hospital. Hence, more of them could not be interviewed early in their hospitalization. Furthermore, a higher percentage of patients at the university hospital did not speak English (28.0% vs. 8.7%), and the greater need for interpreters there caused delays.

The discharge managers at both sites were able to use the process outlined in the IMDP to generate a workable discharge plan for all patients. The plans were reflective of the initial and/or ongoing patient assessments.

Table 2   *Completion of the OSCA*

	University Hospital (%)	Community Hospital (%)
Completed	100	100
Not completed	0	0
Completed within 3 days of admission	36.0	69.6
Completed after 3-day time frame	64.0	30.4

Outcomes Evaluation

Resource use. At the university hospital, the core participants required an average of 94.5 minutes over the course of 5.2 meetings to plan for each patient's discharge. At the community hospital, planning for each patient's discharge required an average of 139.4 minutes over the course of 4.4 meetings. Almost all of the difference in discharge-planning time was accounted for by the time spent completing the OSCA (39.4 vs. 72.4 minutes). In both hospitals, the average amount of time spent per day per patient on discharge planning was relatively small — 6.8 minutes at the university hospital and 19.3 minutes at the community hospital.

The average amount of time that other health professionals were involved was 20.2 and 13.3 minutes, respectively, at the university and community hospitals. These other health professionals included various members of the multidisciplinary team and specialists/consultants. On average, more professionals at the university hospital were required to elaborate the final discharge plan than at the community hospital: four versus one.

Patients at the university hospital exceeded the national average length of stay for elderly patients by 3.4 days, whereas those at the community hospital fell short of the national average by 3.3 days. Of the 34 patients reached by telephone at 6 weeks post-discharge, none had experienced a re-admission. However, two patients from the university hospital had experienced a fall: one at home and one during inpatient rehabilitation.

Respect for persons. At both sites, patients were involved, across the hospital stay, in more than 70% of the total amount of time required for discharge planning, whereas families were involved approximately 40% of the time. Patients and families were involved more often than either the physician (39% at the university hospital and 4% at the community hospital) or the community person (< 10% at both hospitals).

The majority of patients and all family members were satisfied with the discharge-planning process. Three patients at the university site who were not satisfied stated, respectively:

> *Not a piece of cake, you know. I was told to go, that's it. I was planning to stay till my legs were down to normal size but Dr. C. insisted that I had to go.*

> *I'm not satisfied. The doctor said that I had to go. I'm still sick but they said that I had to go. I had no choice.*

> *They told me I'm going home and I said okay. What I say no matter. Nobody believed me. [crying]*

These were the only disagreements noted throughout the entire discharge-planning process.

Patients were satisfied with the process for a variety of reasons: people were kind, they got to decide, there was nothing to complain about, and they got to go home. Family members were satisfied because they were involved with the discharge planner in making decisions and were provided with information. They also said that the planning was well done, they were prepared, and they knew what to expect. One patient's son said:

> *We — my sister and me — were presented with the options. My father was given the choice to decide which decision was best for him. We did not want him to think that just because he was old we were going to put him away in a nursing home. Everyone was very supportive and encouraging. There were no surprises. We were kept very informed.*

Results were somewhat equivocal with regard to the discharge managers' satisfaction. The university site manager favoured the model because it articulated the steps in planning, made it easier to describe the plan to someone else, and ensured standardization of practice. The community site manager rate the protocol as "very good" but expressed the following concerns: too much documentation; protocol difficult to incorporate into daily activities because time required for assessment; and large case loads made it difficult to utilize the IMDP.

Overall, the final discharge plans developed in hospital were adequately meeting patients' needs at 6 weeks post-discharge. However, four patients said that they would like to have more help in the following areas: housework, nursing care, and medical care.

Discussion

Caution must be exercised regarding any generalizability of the results because of the limited number of hospital and patient cases. Also, there were no control units allowing us to confidently claim that the results were a direct consequence of the IMDP. Furthermore, the discharge managers had many years of experience in this role. Therefore, it is possible that our results were a reflection of their skilfulness rather than the IMDP itself.

Process Evaluation

The results of the process evaluation confirmed the findings of our pilot study (LeClerc & Wells, 2001): that the IMDP can be operationalized in practice. For patients with several co-morbidities, however, the 3-day time frame to complete the initial assessment may not be achievable. Patients with a number of co-morbidities or those who do not speak English would likely delay the assessment process. Future research could determine whether these factors influence length of stay.

Involving community personnel and the physician in the process was a challenge. This did not negatively affect the quality of the discharge plans for the patients reached on follow-up in our study. However, we believe that their involvement positively affects patient satisfaction with the outcome. Computer technology may facilitate the early and ongoing involvement of community personnel and the physician by virtue of not requiring their physical presence.

Outcomes Evaluation

Resource use. Overall and on a daily basis, discharge planning is not a time-consuming process, despite the common understanding. The most time-consuming portion of the planning process is the initial assessment. Yet if this critical component of planning is compromised it may be to the detriment of the final plan and other patient outcomes. Hospital administrators must consider appropriate case loads to allow for this activity. Also, a future study might examine whether and how individual characteristics of patients and/or discharge managers affect the length of time taken for various protocol activities.

Other health professionals were used less efficiently at the university hospital than at the community hospital (20.16 vs. 13.26 min.), which may be explained by the discharge manager's communicating with professionals during team rounds rather than on an as-needed basis, as prescribed by the IMDP. The challenge for those interested in implementing the IMDP may be to rethink current patient-care practices that employ regular team meetings as the primary mode of communication and decision-making, which may be inefficient from a time perspective.

For those patients we were able to contact via telephone, we found no untoward effects associated with the IMDP's implementation and at 6 weeks post-discharge except for falls in two patient cases. However, we are unable to conclude that the IMDP provides for a safe discharge

plan, given that we lack information on the post-discharge experience for 14 patients in the study.

Respect for persons. Patients can assume a central role in discharge planning, with their input sought at each stage of decision-making. The patient's situation can be captured in a way that ensures a workable and sustainable plan at discharge through the use of the OSCA and regular meetings. Even though it may be seemingly inconvenient, community persons and the physician must be involved, because the information they can provide is essential to patients' and families' informed decision-making.

The majority of patients and families were satisfied with the process because of their involvement and their being well informed, factors also noted by LeClerc and Wells (2001) and Bull et al. (2000). Despite one discharge manager's concern about the time-consuming nature of the IMDP, it would not be prudent to change the protocol, given the positive outcomes reported for patients and families.

Conclusions

The IMDP offers a promising approach to the discharge of elderly patients in that it is comprehensive; resource-efficient in terms of patient, family, and professional involvement; and respectful of persons. It seems that open communication can be balanced with concerns about conserving resources. In moral or ethical terms, the IMDP provides a fair method of making discharge decisions, and it respects the right of elderly patients to become involved in planning and decision-making. It also constitutes a way to ensure accountability with regard to discharge planning. The next logical step in the study of this model is further evaluation in the Canadian and broader context with a larger sample and an experimental design.

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Authors' Note

Appendix 1 *Discharge Planning Practice Protocol:*
Protocol Elements, Sequence of Activities, and Timing of Activities

Protocol Element	Sequence of Activities	Timing of Activities
1. Assessing the discharge situation	A. Conduct pre-admission and/or admission assessment of the patient and family (use "One Stop Access Client Assessment" form).	Within 3 days of admission
	B. Through personal communication, discuss and determine the initial expectations of the following persons about the patient's discharge needs and goals: • the patient and the family member most responsible for assisting with the discharge • the attending doctor • the relevant community person • other health professional(s) directly involved in the care of the patient.	Within 3 days of admission
	C. With the community person, provide the patient and family member with information about programs and services that can potentially meet their needs at discharge and determine the basis of their preferences.	Within 3 days of admission
2. Developing and writing initial discharge plan	A. Ensure that the patient, family, attending doctor, relevant community person, and other professional(s) directly involved in the patient's care have the opportunity to provide input into the writing and discussion of the initial discharge plan.	Within 3 days of admission
	B. Write the initial discharge plan (use "Initial Plan" form).	Within 3 days of admission

Appendix 1 (cont'd)

Protocol Element	Sequence of Activities	Timing of Activities
	C. Negotiate and confirm initial plan with all those involved in the patient's care (see 2A).	Within 3 days of admission
	D. Record all meetings/contacts with participants (use "Discharge Planning Meetings / Contacts" form).	At time of meeting/contact
3. Involving consultants in the patient's care and discharge plan	A. Ensure timely referral to consultants identified as important to the patient's care by those directly involved in that care (see 2A).	Within 24 hours of identification of need
	B. Through personal communication, determine the consultant's expectations regarding the patient's discharge needs and goals.	Within 24 hours of the consultant's completed assessment
	C. Record all meetings/contacts with consultants (use "Discharge Planning Meetings/Contacts" form).	At time of meeting/contact
4. Developing, writing, and modifying the updated discharge plan	A. Ensure that the patient, family, attending doctor, relevant community person, other professional(s) directly involved in the patient's care, and consultants have the opportunity to provide input into the development, writing, and modification of the initial discharge plan.	PRN as new information is obtained regarding the clinical, functional, or social situation
	B. Write the updated discharge plan (use "Updated Plans" form).	Within 24 hours of receiving new information
	C. Negotiate and confirm updated discharge plan with all participants (see 5A).	Within 48 hours of writing updated plan

	D. Record all meetings/contacts with participants (use "Discharge Planning Meetings/Contacts" form).	At time of meeting/contact
	E. Monitor updated discharge plan so that it is congruent with knowledge about the patient's evolving clinical, social, and functional condition.	As knowledge about the patient's clinical, social, and functional condition emerges
	F. Modify the discharge plan as new information is obtained, in collaboration with participants immediately involved in the patient's care (use "Updated Plans" form).	Within 24 hours of receiving new information
5. Developing and writing the final discharge plan	A. Coordinate the involvement of patient, family, attending doctor, relevant community person, and other professional(s) directly involved in the patient's care in negotiating and writing the final discharge plan.	48 hours prior to discharge
	B. Write the final discharge plan (use "Final Discharge Plan" form).	48 hours prior to discharge
	C. Negotiate and confirm the final discharge plan with participants.	48 hours prior to discharge
	D. Record all meetings/contacts with participants (use "Discharge Planning Meetings/Contacts" form).	At time of meeting/contact
	E. Ensure that medications, treatments, and supplies and other services are available and will be in place at discharge.	48 hours prior to discharge
	F. Ensure that the discharge order is written.	24 hours prior to discharge

Appendix 1 (cont'd)

Protocol Element	Sequence of Activities	Timing of Activities
	G. Determine the readiness of the patient and family for discharge. Do they have a good understanding of the medical condition and related treatments, and of the programs and services that will be provided at discharge?	48 hours prior to discharge
6. Implementing and monitoring the discharge plan post-discharge	A. Maintain telephone contact with patient and family (initiated by discharge director and/or by patient and/or family), in order to: • monitor patient's progress and the appropriateness of the final discharge plan, • modify plan with the community-based professional who is involved, and • record patient and family events post-discharge.	Contact at 2 and 6 weeks post-discharge

A Critical Review and Synthesis of Literature on Reminiscing With Older Adults

Diane Buchanan, Ann Moorhouse, Lucy Cabico, Murray Krock, Heather Campbell, and Donna Spevakow

Le récit de souvenirs est une intervention qui a été utilisée indépendamment auprès de différentes populations depuis plusieurs années, dans le cadre des soins infirmiers. Une analyse critique de la documentation portant sur l'approche du récit de souvenirs a été réalisée en trois étapes : l'identification des études devant faire l'objet de la recherche, l'examen de ces études pour assurer qu'elles soient fondées sur des recherches et une évaluation critique de celles-ci. L'analyse a permis de clarifier les définitions opérationnelles de l'approche fondée sur le récit de souvenirs et le récit de vie. Un examen de nombreuses études a révélé que seules quelques-unes d'entre elles s'appuyaient sur un processus de recherche. Les autres études présentaient aussi un intérêt sur d'autres plans. Par exemple, certaines offraient des pistes pour la conception de programmes d'intervention axée sur le récit de souvenirs et le récit de vie faisant appel à la créativité et ciblant des groupes d'âges spécifiques.

Reminiscing is an intervention that has been used independently in nursing with different populations for many years. A critical analysis of the literature on reminiscing was carried out in 3 stages: identification of the studies to be included, review of the studies to ensure that they were research-based, and critical appraisal of the studies. The analysis resulted in clarity regarding the operational definitions of reminiscing and life review. Of the many studies reviewed, only a handful were research-based. The others were valuable in other respects, such as providing guidance for the design of imaginative and age-related reminiscing and life-review programs.

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Reminiscing as an intervention has been used independently in nursing with different populations for many years. Butler (1963) defines it as the "act or habit of thinking about or relating past experiences, especially those considered personally most significant," Hammer (1984) as a "method of holding onto the self while letting go of some personal situation." In other words, through remembering the past, persons may come to terms with their regrets and realize their achievements.

There is general agreement among health-care professionals that reminiscing has benefits for residents of long-term-care (LTC) facilities. Consequently, there is a trend to introduce more reminiscing programs in LTC facilities both in group settings and on a one-to-one basis. However, other terms have also been used to describe the process of reminiscing, and this has resulted in confusion about what actually constitutes reminiscing. The most commonly used alternative term is "life review." Life review is actually a subset of reminiscing and involves a structured approach to searching for and reviewing meaning in one's life.

The Relationship Centred Care Research Group of the Collaborative Research Program – Rehabilitation and Long Term Care is dedicated to the study of ways to develop and support caring relationships between nurses and residents of LTC facilities. Given the growth of reminiscing in LTC and the need for evidence-based practice, the Research Group decided to focus on the development and evaluation of reminiscing programs in LTC facilities. This article describes the findings of a review of the literature on reminiscing and life review, as used with older adults, in order to clarify the meaning and usage of the terms "reminiscing" and "life review" and to identify and describe the manifestations of reminiscing, how it is used in LTC facilities, and factors that support or discourage reminiscing in LTC facilities.

Method

The literature includes several theoretical articles describing the manifestations and implementation of reminiscing (Burnside & Haight, 1992; Haight, 1991; Haight & Webster, 1995; Kovach, 1991a, 1991b; Parker, 1995). In order to develop a program for the implementation of reminiscing in an LTC environment, it is important to appraise the quality of studies that have tested the theoretical underpinnings of reminiscing as an intervention. The literature review was carried out in three stages: (1) identification of the key studies to be included in the review, (2) review of the articles to ensure they were research-based, and (3) critical appraisal of the research studies.

Stage 1

Stage 1 consisted of an online search of the following health and social-science databases from January 1990 to December 1997: CINAHL, MEDLINE, and PsychINFO. Studies were included in the review if they: (a) were research-based as opposed to descriptive, (b) involved persons aged 65 and over, (c) focused on reminiscing or life review, and (d) were published in English. A total of 105 books and journal articles that met these criteria were retrieved.

Stage 2

A detailed review of the studies was conducted using standards adapted from a tool developed by Forbes and Strang (Forbes, 1998; Forbes & Strang, 1997). Their study examined a variety of interventions and offered a detailed process for literature review. Our study was more focused in terms of population, location, and intervention. The Forbes and Strang Validity Rating Tool ranks research as pass, moderate, or fail. For our study, it was necessary to modify their criteria as noted in Table 1. The Forbes and Strang pass-moderate-fail ratings were changed to pass-fail ratings when the reminiscing studies would not have met their complete criteria for pass. For the design and inclusion criteria, there was insufficient information to meet the highest pass rating. The typical confounders did not appear to be well controlled. In terms of data collection and statistical analysis, no study met all criteria of well described, pre-testing and investigators blinded. Likewise, multivariate statistics were not universally used so again the higher pass rating used by Forbes and Strang was not met.

We used a Relevance Tool to add the criteria of older adults in LTC facilities and each study's operational definition of reminiscing or life review to strengthen the design. Ater screening of the 105 articles using the research process, 67 studies remained.

Stage 3

The final stage consisted of a critical appraisal of the 67 studies and a synthesis of the findings. The synthesis integrated the quantitative and/or qualitative findings across studies. The data from Stage 2 were used to critique the screened studies and, based on their strength as research studies on reminiscing or life review, we categorized the studies as strong, moderate, or "insufficient documentation." The outcome of this Stage 3 process was seven studies rated as strong, four studies rated as moderate, and four studies with insufficient data to rate

Table 1 *Summary of Key Differences in Rating*

Forbes & Strang Validity Rating Tool	Reminiscing Validity Rating Tool
Design – pass moderate fail	Design – pass fail
Inclusion – pass moderate fail	Inclusion – pass fail
Consent – pass moderate fail	Consent – pass moderate fail
Attrition – pass moderate fail	Attrition – pass moderate fail
Confounders control – pass moderate fail	Confounders control – pass fail
Data collection – pass moderate fail	Data collection – pass fail
Statistical analysis – pass moderate fail	Statistical analysis – pass fail
	Location – LTC/community – pass moderate fail
	Operational description of REM/LIFE REVIEW – pass moderate fail
Overall Assessment	Overall Assessment
Strong – no fail rating and no more than 2 moderate ratings	Strong – no fail rating and no more than 2 moderate ratings
Moderate – no fail rating and more than 2 moderate ratings	Moderate – no fail ratings and all other scores must be pass or moderate
Weak – 2 or less fail ratings	Insufficient data – below the moderate rating
Poor – more than 2 fail ratings	

them as strong or moderate. The following sections provide an overview of the insufficient data, strong, or moderate studies. The synthesis complemented the critical appraisal by integrating the quantitative and/or qualitative findings across studies.

Overview of Relevant Studies

Among the excluded studies were several that were primarily about instrument research (Bramlett & Gueldner, 1993; Habegger & Blieszner, 1990; Kovak, 1993; Merriam, 1993; Webster, 1993; Wong & Watt, 1991) and the majority of studies that lacked sufficient information to complete most of the categories of the Validity Rating Tool — that is, they lacked sufficient information related to the research process to rate them. There remained 11 studies rated strong or moderate (Table 2), which are discussed below.

Table 1 *Reminiscing Studies With Older Adults*

Study	Participants/ Setting	Operational Term/Method	Research Design and Data Analysis	Outcomes	Generalizability in LTC and Usable Factors
S1 – Haight (1992): Long-term effects of a structured life review process	N = 51 randomly selected community elders	Method clearly described — three groups: experimental life review, friendly visit group, no-treatment group for 6 weeks	Pre-test/post-test, and retest at 1 year: life satisfaction, ADLs psychological well-being, and depression	No significant change in four dependent variables between post-test and retest	All living at home
S2 – Haight & Dias (1992): Examining key variables in selected reminiscing modalities	N = 240 randomly selected from nursing homes (71) and community (117)	Life review clearly described: 10 different reminiscing modalities (five group and five individual) for 6–8 weeks	Pre- and post-test on four outcome measures	Structured life review most therapeutic for one-on-one. Group reminiscing best for social support.	Mostly white, middle-class; however, could replicate study and outcomes provide useful suggestions
S3 – Haight, Coleman, & Lord (1995): The linchpins of a successful life review: structure, evaluation, and individuality	N = 18 (three groups of six) community women	Life review clearly described — three groups: life review group, attention control group, and no-contact control group for 6 weeks	Pre- and post-test measures on self-esteem, morale	Life review had impact on self-esteem but not morale. Themes: losses, unresolved issues, happiness, sadness, and fear re: losses	Provides suggestions for group leaders

Table 1 (cont'd)

Study	Participants/ Setting	Operational Term / Method	Research Design and Data Analysis	Outcomes	Generalizability in LTC and Usable Factors
S4 – Habegger & Blieszner (1990): Personal and social aspects of reminiscence: An exploratory study of neglected dimensions	$N = 50$ male and female community seniors	Measured oral (interviews) and silent (self-administered questionnaire) reminiscence for frequency and attitudes towards thinking and talking about the past	Questionnaire piloted. Measures of oral and silent reminiscence compared using T-tests and Pearson correlation.	Silent reminiscing occurred more often than oral. Appropriateness correlates with usefulness, early experiences, and opportunities to reminisce. Some gender differences.	Suggestions made for facilitators and for type of reminiscence based on participants' past experiences and gender
S5 – Sherman (1995): Differential effects of oral and written reminiscence in the elderly	$N = 74$ voluntary community elders: eight groups	Method described — three types of groups: oral/journal reminiscence, oral reminiscence, and autobiography	Pre- and post-test using scales to measure psychological well-being and late-life adjustment and frequency of types of reminiscing	Findings indicated reminiscing through the journal is beneficial	Community group; physical and cognitive changes may limit journal use in LTC
S6 – Cook (1991): The effects of reminiscence on psychological measures of ego integrity in elderly nursing home residents	$N = 54$ randomly selected residents from three nursing homes	Method described — life review, current events group, and no-treatment control group hourly for 16 weeks	Pre- and post-test measures on self-esteem scale, life satisfaction, and depression	Slight trend with reminiscence group rating higher life satisfaction score	Relevant to LTC participants: offered suggestions for replicating study. Anecdotal data: reminiscing contributes to socializing.

Study	Sample	Method	Methodological comments	Findings	Relevance to LTC
S7 – Fry (1991): Individual differences in reminiscence among older adults	N = 140 randomly selected elders, 70 from four nursing homes and 70 from community, matched for gender and age	Method clearly described — reminiscence explored subjective indices of life satisfaction, daily functioning personality characteristics, and goals and purposes in life	Multiple regression used to analyze personality, psychological well-being, and meaning of life as predictors of frequency and pleasantness of reminiscence	No significant difference in frequency of reminiscence between groups. Findings suggest individuals have positive perceptions of psychological well-being, and engage in a number of daily activities.	Relevant to LTC: individuals struggling to find meaning to life in the naturalistic environment may resort to reminiscing
M1 – Beaton (1991): Styles of reminiscence and ego development of older women residing in long-term care settings	N = 75 white women, from six LTC facilities	Method not specified — reminiscing; sentence completion and telling life story through one interview	No control group. Investigators and rater methods controlled. Assessed ego development.	Ego development – associated with reminiscing styles: related to years of education & religious affiliation	Relevant to LTC: "affirming" women had higher levels of ego development; probably best candidates for life review and reminiscence
M2 – Yang & Rehm (1993): A study of autobiographical memories in depressed and nondepressed elderly individuals	N = 27 depressed and 27 not depressed community elders	Method described — reminiscing done through autobiographical memory task to study memory process and depression	Procedure clearly explained. Measure for depression and types of memories.	More pleasant than unpleasant memories recalled	Community elders. Participants, whether or not depressed, recalled more positive than negative events.

Table 1 (con'd)

Study	Participants/ Setting	Operational Term/Method	Research Design and Data Analysis	Outcomes	Generalizability in LTC and Usable Factors
M3 – Burnside (1993): Themes in reminiscence groups with older women	N = 67 convenience women living in the community	Method described — reminiscence guided by eight gender-specific themes selected from literature to elicit simple reminiscence and non-threatening memories	Qualitative data analysis clearly described. Used deductive and inductive methods.	Three most discussed themes that elicited reminiscence: (1) favourite holiday (2) first pet (3) first job	Community women, but process and findings seem relevant to LTC and to replication. Nine specific guidelines offered for group leaders planning to implement an all-women's group.
M4 – Dhooper, Green, Huff, & Austin-Murphy (1993): Efficacy of a group approach to reducing depression in nursing home elderly residents	N = 16 randomly selected depressed nursing-home residents	Twenty-four tape recordings. Details of sessions not clearly described — reminiscing and problem-solving groups to decrease mild to moderate depression for 9 weeks.	Pre- and post-test on depression – loss of control subjects – comparison problem	Three-fourths of reminiscing group were free of depression after 9 weeks; depression level was less in control group	Findings suggest that an eclectic approach to reducing depression may be effective

Strong Studies

The Validity Tool identified seven studies as strongly supporting the value of using reminiscing with an older adult population (Table 2). All were relevant, had an adequate sample size, and produced reliable data. In all studies, the participants were capable of completing one or more tests regarding their mental status, mood, and quality of life. Not all articles discussed the matter of whether the participants were capable of consent; however, given their inclusion in the study and the difficulty of the tests, consent is assumed. The participants were recruited from institutions and the community and included more women than men. Each study is summarized below, followed by summary remarks. Three of the articles are co-authored by Haight, a leading investigator in the study of reminiscing. The first four strong studies used the reminiscing process referred to as life review. The other three used a broader, more generic version of reminiscing.

(S1) In "The long-term effects of a structured life review process," Haight (1992) examines the effects of a structured reminiscing process through a pre- and post-intervention design in which each participant completed four tests: Life Satisfaction Index, Bradburn's Affect Balance Scale, Zung's Depression Scale, and the Activities of Daily Living Instrument. Re-tests completed 1 year after the intervention showed no significant change in the scores. Haight concludes that life review may help participants to maintain ego integrity. However, she warns that the lasting effects may be attributable to not only life review but myriad factors, including the ageing process.

(S2) In "Examining key variables in selected reminiscing modalities" (Haight & Dias, 1992), the subjects participated in one of 10 reminiscing modalities during an 8-week period and completed pre- and post-measures of life satisfaction, psychological well-being, self-esteem, and depression. This study highlights the different ways of conducting reminiscing sessions and life review. The authors define life review as a structured, evaluative reminiscing process that is most effective when used on a one-to-one basis. They define reminiscing as the random recall of the past that is performed most effectively when engaged with peers in a group format. They suggest life review is of therapeutic value for persons dealing with depression and grief, while reminiscing is of value in promoting socializing and peer support.

(S3) In "The linchpins of successful life review: Structure, evaluation and individuality," Haight, Coleman, and Lord (1995) make a major contribution to scholarship on life review. They point out that the "indi-

vidually structured" life-review process is the only life-review process systematically evaluated. They tested the effectiveness of life review employing the methods used in the Haight and Dias (1992) study. Of three groups, a life-review group and two control groups, the life-review group showed the most significant increase in self-esteem scores.

Based on the findings from studies S2 and S3, the authors argue that three elements are needed. First, the intervention must be structured to cover the entire life; activities such as writing an autobiography or writing about major life themes are recommended. The second element is an evaluation or valuation of the life lived by the participant; the goal of evaluation is to reach the stage of ego integration. The third requirement is one-to-one reminiscing with an active listener skilled in life review and capable of helping the participant to reintegrate his or her memories.

(S4) In "Personal and social aspects of reminiscence: An exploratory study of neglected dimensions" (Habegger & Blieszner, 1990), the key finding concerns the leader of the life-review group more than the actual participants. The conceptual foundation of the study was symbolic interaction and social exchange. The subjects completed both a reminiscing questionnaire and a self-report questionnaire. The results suggest that the structured reminiscing group is a form of life review and that "leaders" should consider the social skills of the potential reminiscing candidate. The authors emphasize that silent and oral reminiscing are different modalities that need further research.

(S5) In "Differential effects of oral and written reminiscence in the elderly," Sherman (1995) examines the merits of reminiscing groups for increasing social support. Two groups were compared, an oral/journal reminiscing group and a strictly oral reminiscing group. The oral/journal group scored higher on the Ego Integrity Scale. The results indicate that reminiscing through the use of a writing journal is beneficial.

(S6) In "The effects of reminiscence on psychological measures of ego integrity in elderly nursing home residents," Cook (1991) examines whether reminiscing influences the attainment of ego integrity. Unlike the previous studies, this study used participants from nursing homes and also used control groups. Cook explores the idea of positive reminiscing and describes the strategies used. Like the other researchers, Cook found no statistically significant evidence of the psychological effects of reminiscing. However, there seemed to be a positive socializing effect from being in a group.

(S7) In "Individual differences in reminiscence among older adults: Predictors of frequency and pleasantness ratings of reminiscence activity," Fry (1991) explores the relationship of the benefits of reminiscing with the personality traits of the participants. Community residents and nursing-home residents were interviewed using two questions from the Reminiscing questionnaire and completed nine other questionnaires. The predictors of experiencing reminiscence as a pleasant activity were found to be numerous, including: past life satisfaction, openness to the experience of reminiscing, ego-strength, control of their life, and frequency of negative life experiences. Fry suggests that reminiscing about personal losses may be unpleasant in the short term but can be productive and even therapeutic in the long term.

Summary. The seven studies that met the stringent criteria for the "strong category" provide important information about the value of reminiscing. The assumption that these processes result in psychological well-being was examined and challenged. These studies demonstrate that the difference between reminiscing and life review must be considered before either type of intervention is planned or implemented. The goals of the process, the selection of participants, and the preparation of the leaders must be considered. All the participants in the studies appraised were mentally high functioning, so the findings cannot be assumed to apply to residents of LTC, many of whom have dementia.

Moderate Studies

The Validity Tool identified four papers with moderate evidence supporting the value of using reminiscing with an older adult population. All four of these studies (Table 2) used the broader concept "reminiscing."

(M1) In "Styles of reminiscence and ego development of older women residing in long-term care settings" (Beaton, 1991), the participants were asked to recount their life story in order to elicit the particular styles of reminiscing that could be explained by levels of ego development and to complete an ego-development questionnaire. The styles of life story reminiscing were labelled Affirming, Negating, or Despairing. The responses were used to demonstrate the participants' core level of ego development, which included impulsive, self-protective, conformist, conscientious, autonomous, and integrated. "Affirmers" had higher levels of ego development than "non-affirmers." The results indicate that ego development may account for differences in style of reminiscing.

(M2) In "A study of autobiographical memories in depressed and non-depressed elderly individuals," Yang and Rehm (1993) used a single 2–3-hour interview to examine how participants reminisced based on particular words that trigger memories. The participants were also asked to recall both sad and happy events. Although this study was not longitudinal, some of its findings merit further exploration. One finding was that whether depressed or not, the participants recalled more positive than negative events.

(M3) The primary purpose of Burnside's (1993) study, "Themes in reminiscence groups with older women," was to determine what themes in reminiscing elicit the most discussion of memories. Based on a literature review, eight themes were chosen to elicit simple reminiscing and non-threatening memories considered appropriate for an all-female group. Qualitative data were analyzed to determine the amount of reminiscing each theme elicited. The author offers nine guidelines for group leaders planning to implement an all-woman reminiscing therapy group.

(M4) In "Efficacy of a group approach to reducing depression in nursing home elderly residents" (Dhooper, Green, Huff, & Austin-Murphy, 1993), the participants in the reminiscing group attended nine weekly sessions in which topics ranged from reminiscing about childhood to exploring feelings associated with living in a nursing home; no information is provided on the activities of the control group. The two groups were measured on depression, orientation, cognitive functioning, and mental health. The results suggest that institutionalized older adults can benefit from a group approach that enables the sharing of life histories, the expression and management of feelings, and the acquisition of problem-solving skills.

Discussion

Key findings were consistent throughout the studies reviewed and had also been noted in the theoretical literature. One important finding was the distinction between reminiscing and life review. In the literature, there is a convergence of the concepts reminiscing and life review. As a starting point, we were guided by Burnside and Haight's (1992) comparative concept analyses of reminiscing and life review. The following points about reminiscing and life review were gleaned from their concept analyses and subsequent articles: Reminiscing is a way of thinking and talking about one's life. It is an unstructured or structured process that may occur alone, with another person, or in a group.

Reminiscing can be done for the process alone or can lead to conclusions about a person's life, life's meaning and significance. It is a global concept, which subsumes a number of other concepts. On the other hand, life review, a subset of reminiscing, is a structured approach to reviewing and looking for meaning (or lack of meaning) in one's life. This tends to be conducted at set times, and to involve a guide through different or sequential aspects of a person's life.

Several distinctions that were identified repeatedly throughout the findings of the strong and moderate studies reflect or add to the above descriptions.

The Material Examined

Reminiscing, as an intervention, is an interaction between two or more people. The resminiscence process is one of eliciting memories of past events or experiences. In contrast, life review is a process that recalls the entire life span and can be shared verbally or non-verbally.

The Therapeutic Goals

Reminiscing can serve many purposes: it provides a basis for socializing, provides a basis for groups, reduces isolation, and/or improves quality of life. On the other hand, life review tends to serve more structured purposes such as reviewing the worth of one's life and thus of one's self-esteem; it is often done during a time of crisis such as preparing for death. Reminiscing and life review have taken place within the community, in institutions, and in long-term and acute-care facilities. The location is influenced by the specific purpose of the activity, such as whether "props" or written material will be used or whether a group environment will be necessary.

The Process and the Players

Reminiscing, as an intervention, most often takes place within a group, and depending on the goals can be led by a caregiver with minimal education in group work. However, reminiscing can also take place when personal care is being provided (bathing, mealtimes). Often, the caregiver uses his or her intuition and experience to engage in a reminiscing conversation with the resident. Usually, life review occurs in a one-to-one situation with a professional who has training in the processes of individual interactions and life review.

The Benefits

A considerable amount was written describing the processes used in specific studies. Much less was written about the study variables, which give more credence to the projected or stated outcomes. Benefits of the broader reminiscing process were not established because five of the studies were about life review. Life review was beneficial but not in the way assumed by many: feelings of well-being were not the immediate result. Instead, analysis of one's life was associated with a variety of feelings that included sadness, loss, and pride. In the long run, integration of the past with the present was an expected benefit.

An interesting observation was that many of the research papers are silent on the topic of consent. Given the fact that the studies exposed the participants to risk and offered them questionable benefits, mention of the consent process seems a reasonable expectation.

Conclusion

In terms of our goals, we were unable to meet all three because the literature reviewed was predominantly about life review rather than reminiscing and did not include the expected details. However, the project was valuable. There is a paucity of research evidence on therapeutic reminiscing. The critique of the articles addressed the need for those using these interventions to be very clear about the reminiscing activities and to clearly articulate the research methods used. Without clear statements regarding the methods used, neither clinicians nor researchers are able to confidently use the findings from such studies. While the research papers involved higher functioning persons than those usually found in LTC facilities, the evidence from the studies appraised about reminiscing and life review can inform the next stage of the research program.

A major value of the review was obtaining clarity regarding the operational definition of reminiscing and life review. The operational definition of reminiscing for the Relationship Centred Care Program is: Reminiscing is a way of talking about one's life. It can occur as an unstructured or structured process that may occur alone, with another person, or in a group. As an intervention it involves eliciting memories from the resident. Reminiscing is led by a professional who can identify the purposes of the intervention and the needs of the reminiscers. Life review, on the other hand, is a subset of reminiscing and involves a structured approach to reviewing and looking for meaning (or lack of

meaning) in one's life. It is conducted at set times, and involves a guide through different or sequential aspects of a person's life.

A further conclusion of this study is that any investigation of reminiscing should include several guidelines. There must be clarity about: the purpose of the intervention; the sample size and the consent process, with respect to LTC residents; training of reminiscing leaders (practitioner, nurse) and availability of professional mental health resources should participants become distressed; and the location, time of day, frequency, and length of the intervention. In addition, the reminiscing activity/activities must be clearly described, and the clinical and demographic data must be sufficient to describe the participants and identify limitations.

Of the many articles initially identified, only a handful were research-based. The others were valuable in other respects, such as offering useful guidance on the design of imaginative and age-related reminiscing and life-review programs, and descriptions of the rewarding experiences of caregivers and residents. This review will help us to move to the next stage of the research program, the development and evaluation of reminiscing in long-term care.

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Authors' Note

Twentieth-Century Social and Health-Care Influences on Location of Death in Canada

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Des soins adéquats, prodigués dans des lieux appropriés, ne peuvent être offerts aux mourants en raison d'un manque de compréhension quant aux lieux habituels où se vivent la phase terminale et le décès, et quant aux facteurs influant sur les lieux de décès. Cet article présente les résultats d'une étude historique multidisciplinaire des éléments du 20ᵉ siècle qui influent sur les lieux de décès au Canada. Il s'appuie sur une recherche qui révèle qu'au Canada, pendant la plus grande part du 20ᵉ siècle, les décès surviennent surtout en milieu hospitalier, et que ce taux est à la baisse depuis 1994. Cette étude a identifié deux facteurs clés en ce qui a trait au lieu de décès : (1) des transformations dans le domaine des soins et du système de santé ont relégué les soins aux hôpitaux et suscité chez le public des attentes de soins en milieu hospitalier qui sont efficaces et curatifs – l'augmentation du taux de décès en milieu hospitalier au 20ᵉ siècle peut donc être attribuée au fait que les soins, jadis prodigués à domicile, ont été transférés dans les hôpitaux; et (2) la diminution de la disponibilité des soignants naturels. Pour les malades chroniques et les personnes en phase terminale, plusieurs changements ont réduit les possibilités d'être soignés en milieu familial, notamment la participation croissante des femmes au marché du travail et le fait que l'exercice de la profession infirmière est passé du foyer aux hôpitaux. Bien que des services sociaux et des soins de santé ont été mis sur pied dernièrement pour la clientèle à domicile, ce soutien n'est pas, de toute évidence, aussi important que celui accordé aux soins hospitaliers. Les résultats de cette recherche indiquent que le lieu de décès constitue un facteur important dans l'étude et la planification d'améliorations au bénéfice des personnes en phase terminale.

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Providing the right care, in the right place, to dying persons is hampered by a lack of understanding of where death and dying normally take place and ignorance about what influences location of death. This paper reports the findings of a multidisciplinary historical investigation of 20th-century influences on location of death in Canada. It builds on a study that found a hospitalization-of-death trend in Canada over much of the 20th century but a reduction in hospital deaths beginning in 1994. This study found 2 key influences on location of death: (1) health-care and health-system developments that consolidated care in hospitals while also raising and sustaining public expectations of beneficial if not curative hospital care — the rising hospital-death rate throughout the 20th century can thus be considered an outcome of the shift of illness care from the home to the hospital; and (2) reduced availability of home-based caregivers. A number of developments limited the availability of home care for chronically ill and terminally ill persons, including the increased participation of women in the workforce and the shift in nursing from private home duty to hospitals. Although some health and social support for home care has developed recently, this support clearly does not match that for hospital care. These findings indicate that location of death is an important focal point for studying and planning improvements in end-of-life care.

One of the most serious concerns today about death and dying is extensive and expensive treatment-oriented care. Although some Canadian research indicates that terminally ill people are often recognized as such and treated compassionately (Wilson & Truman, 2001), a recent large-scale study of hospital care found aggressive care until death to be the norm in the United States (SUPPORT Principal Investigators, 1995). The impact of extensive cure-oriented diagnostic testing and treatment has led one nurse to conclude: "first you suffer, then you die" (Curtin, 1996, p. 56). Futile, cure-oriented end-of-life care is particularly troublesome in light of the considerable palliative-care advances that have been made. Palliative care has become an effective, comprehensive, comfort-oriented, broad-based approach, irrespective of the location of care, for improving the quality of life of dying individuals and their families (Canadian Palliative Care Association, 1997).

Yet palliative care has not exactly flourished in Canada. Most hospitals still do not have palliative-care teams or programs to plan and provide care to dying persons (Health Canada Working Group, 1997; Roy, 1999). Community-based palliative-care programs are increasing in number but are inadequate to meet current needs (Health Canada Working Group; Wilkins & Park, 1998), let alone the future needs of a growing and ageing population (Chui, 1996; Statistics Canada, 2000).

Providing the right care, in the right place, to dying persons is made all the more difficult by considerable knowledge gaps. Although death in hospital is a common occurrence (Heyland, Lavery, Tranmer, Shortt, & Taylor, 2000), no comprehensive reports on location of death in Canada exist for planning or policy purposes. Health-services planning for dying persons is hampered by a lack of understanding of

where death and dying take place, the factors that influence location of death, and whether important shifts in location of death and dying are occurring. To address these knowledge gaps, an investigation of 20th-century Canadian trends in location of death and factors influencing location of death was undertaken.

Research Methods

The first phase of the investigation involved an analysis of three Canadian mortality databases to identify 20th-century trends in location of death. The findings of this analysis are reported elsewhere (Wilson et al., 2001). Two findings are critically important: a longstanding hospitalization trend (culminating in a peak incidence of 80.5% of all recorded places of death in 1994), and a reduction in hospital deaths following 1994.

The second phase involved an historical study of 20th-century social and health-care influences on location of death. To ensure broad-based, comprehensive data collection and diverse disciplinary perspectives on group data analysis and synthesis, the project was undertaken by a multidisciplinary six-member team: a nurse, a palliative-care physician, a health-care historian, a nurse gerontologist/psychologist, a philosopher/ethicist, and a sociologist. Each researcher had a distinct focus of inquiry and committed to searching a distinct selection of library databases (see Appendix 1). To enhance trustworthiness of data collection and analysis, all members of the team attended a workshop on historical data collection and historical-comparative data-analysis methods.

Extensive quantitative and qualitative data were sought by each researcher and his or her research assistant(s), with historical-comparative methods being used to organize, critique, compare, and synthesize data (Hamilton, 1993; Sarnecky, 1990). As influences can vary greatly from one country to another, only Canadian information was sought.

More specifically, after data from the first phase of the investigation and preliminary data had been reviewed, the data search was divided into four eras: the early 20th century (1900–39), the development of Medicare era (1940–69), the initiation of palliative-care era (1970–89), and the contemporary era (the 1990s). This division permitted a contextualization and categorization of influences that proved to be impossible when a decades-based approach was attempted. Historical research is often undertaken and reported in such a chronological

context, as developments in one period can influence those in subsequent periods (Colton, 2000).

Each researcher used data triangulation and judgements about the dependability of data to prepare four reports, one for each era, on location-of-death influences. The reports were circulated to all researchers prior to group meetings, with meetings taking place after all reports for an era had been prepared. Each researcher thus developed a discrete database and understanding of era-based influences on location of death. The researchers also came to a common understanding, through group analysis and synthesis of findings, of location-of-death influences first for each era and then for all eras combined. The group thus consensually approved and validated the findings presented below.

Findings

Early 20th Century (1900–39)

Many early developments facilitating hospital-based health care were identified. Two critical location-of-death influences became apparent: increased availability of hospital-based care, and an increased need for and acceptance of hospital-based care.

The increased availability of hospital-based care was due in part to rapid growth in the number of hospitals. Agnew (1974) notes that in 1870 there were only a few hospitals across Canada but in 1929 there were 886 (with 74,882 beds). Another example of rapid hospital growth was provided by the principal investigator through an analysis of annual hospital reports housed in the Provincial Archives in Edmonton. In 1905, there were only 11 hospitals in Alberta, but by 1939 there were 93 (compared to 120 currently for a much larger population).

Hospitals at the turn of the 20th century were often private homes converted to hospitals by charitable or religious groups (Agnew, 1974). Although most were small, hospitals were considered necessary for a variety of reasons, such as to attract settlers, but the most common reason was to meet the health-care needs of people living in the immediate area (Agnew, 1974; Middleton, 1919). As most early hospitals in Canada were voluntary enterprises, they often provided care even when there was little possibility of payment (Agnew, 1974). Hospitals tended to provide care only when it was not available in the home (McGinnis, 1988).

There is considerable evidence that hospital care was increasingly needed during this era, one reason being rapid population growth as a result of immigration (MacDougall, 1994), with single immigrants, and married immigrants who arrived in advance of their families, having to rely on hospitals when ill. Industrialization and urbanization, two developments in the early to mid-1900s (Ostry, 1994), disrupted the family unit and thus reduced the ability of families to provide care in the home. The conscription of men during the two world wars also served to reduce the ability of families to provide health care in the home (McPherson, 1996). Not only were able-bodied men removed from the home, but able-bodied women were often employed outside the home. In addition, the wars produced many injured veterans. At the end of World War I alone, 173,000 disabled and wounded men returned to Canada (MacDougall). These veterans could not always be cared for at home, and governments felt a responsibility to them (MacDougall; Ostry). Municipal governments were the first to take concrete steps to ensure the availability of hospital care. By 1924, many hospitals had come under the control of municipal governments as a result of their providing secure funding (Middleton, 1919).

Regardless, most sick people in the early 1900s received care in private residences (McGinnis, 1988). Home care for both the sick and the dying was considered the norm (McPherson, 1996). Care by family members also eliminated the need to pay for hospital care or for private care in the home. Significant limitations on the efficacy of health care also served to temper public reliance on and demand for hospital care. Despite advances in surgical techniques and in radiation (George & Gerber, 1915), few serious illnesses or diseases were curable in the 1900–39 era (Bell, 1900; Munroe, Hoare, & Cristall, 1939). The hospital was considered a place of death, as indeed death commonly occurred there (Agnew, 1974; Buckley, 1988; MacPhail, 1904; Rozovsky, 1974), partly due, perhaps, to a lack of effective medications (Blackader, 1916): antibiotics did not become available until after World War II (MacDougall, 1994; McGinnis), and anaesthesia and pain medications were not in common use (Roland, 1985).

Yet the public's faith in health care increased in this era. Public-health measures initiated by government greatly reduced infectious disease and death rates (Harding le Riche, 1979). Immunization was almost routine across Canada by the time of World War I (Harding le Riche). Similarly, by 1920 milk pasteurization and other public-health measures had greatly reduced the incidence of tuberculosis, a major cause of death until then (MacPhail, 1904; Zilm & Warbinek, 1995).

X-ray technology, electrocardiography, and laboratory testing of blood and bodily fluids also came to be used widely (Agnew, 1974). Hospitals served as the physical location of these technologies, along with the experts required to operate them. Early diagnosis became a medical preoccupation (Bell, 1990). Insofar as early detection helped to save lives, the hospital was transformed, in the 1920s and 1930s, from a place where one went to suffer and die, to a place where one's life might be saved (Agnew, 1974).

Nursing developments also raised public confidence in hospitals, thereby promoting a shift of care from the home to the hospital. Stringent nursing programs were instituted in hospitals at the turn of the 20th century, with staffing composed primarily of student nurses (McPherson, 1996). Graduate nurses normally provided care in the home (McPherson). Often, this care was palliative, or comfort-oriented (McIlveen & Morse, 1995). For instance, early records of the Victorian Order of Nurses indicate that half of its home-care clients were dying ("What is the V.O.N.?," 1943). Private home visits could be of short duration, but long-term home nursing care was also common (McPherson). The 1920s recession and 1930s Depression, however, made hospitals a much more attractive work setting for nurses, as for physicians, due in part to the dependability of public versus private funding (McPherson; Weir, 1932). This shift in work setting served to reduce the number of persons available to provide skilled health care in the home, while increasing the quality and desirability of hospital-based care.

Other, less tangible, developments also influenced the hospitalization trend. The dual development of health-care professionalism (Rozovsky, 1974) and technological advances reflected, as well as fuelled, the emerging ideology of logical positivism — that science and technology can understand and control the natural world (Ostic, 1940). The increased faith in science was accompanied by a decrease in the social power of religion (Stingl, 1997). One of the most significant outcomes of these changes was a shift in medical focus, from the patient as a subject of observations (about his or her condition) made by the physician, to the patient's body as a subject of observations made by machines (Stingl). The subjective meaning of illness and death began to be eclipsed in significance by their technological management in a hospital setting. In summary, many developments in the 1900–39 era influenced a shift in care from home to hospital, and these same developments would support a shift in death and dying from home to hospital.

Development of Medicare Era (1940–69)

Prior to the early 1970s, when access to hospitals and medical care was assured across Canada, two federal government initiatives supported hospital-based care. The first was the National Health Grants, aimed, during the 1940s and 1950s, at increasing the number of hospital beds and raising the quality of hospital care (Vayda & Deber, 1984). These funds were often used to upgrade hospital laboratories and radiology departments. The second development was the passage, in 1957, of the *Hospital Insurance and Diagnostic Services Act,* making hospital care accessible to all Canadians. Yet, while hospital care began to be provided at public expense, home care continued to involve private costs (Donahoe, 1961; Special Report, 1970).

There was considerable demand for nurses and other health-care workers during this era of hospital expansion (McVey & Kalbach, 1995). Employment in the financially secure, familiar hospital environment became the norm for nurses (Canadian Nurses Association Research Unit, 1966; McPherson, 1996). The rising incidence of hospital care and the shift of nurses to the hospital setting increasingly made nurses, as opposed to lay family members, the primary caregivers in cases of serious illness, dying, and death. The public was thus assured of expert care for the ill and dying (Rozovsky, 1974).

Yet the age-old duty of nurses to provide comfort-oriented care to dying persons was at odds with a medical emphasis on cure or life prolongation (Quint, 1967). Comfort-oriented or palliative care did not advance much during this era, perhaps due in part to nurses having come under the control of physicians and hospital administrators (McIlveen & Morse, 1995). In addition, nurses were not united: some advocated for palliative care and publicly funded home care, some for keeping pace with rapidly changing technologies (Miller, 1960).

Three additional interrelated developments influenced the pre-1970 rapid rise in hospital deaths: industrialization/urbanization, changing gender roles, and the social disruption caused by World War II (Guest, 1985; McVey & Kalbach, 1995). During this larger war, more women were needed to work outside the home. Following the war, married women continued to seek paid work outside the home (Chisholm, 1944; McVey & Kalbach), and long-term, home-based caregiving became increasingly less possible as their employment rates grew. The reduced availability of female family members to provide home care is only one explanation, however, for the growing demand for hospital care (Agnew, 1947, 1974).

Open-heart surgery, intubation and ventilation, and cardiopulmonary resuscitation were all pioneered in this era (Grondin, Lepage, & Castonguay, 1964; Minuck & Perkins, 1969). Antibiotics and other advances in drug therapy also raised public expectations about the efficacy of health care. Most advances required care in hospital by physicians, nurses, and other trained specialists (Agnew, 1947). Technological intervention became standard practice in the treatment of life-threatening illnesses (Mair, 1967; Postman, 1993) and the fight against death (Stevenson, 1963).

Health-care advances also served to change the personal impact and meaning of death and dying. Growing awareness that most people could live into old age (Sellers, 1951) helped to replace a centuries-old fear of dying (Wallace, 1951) with the hope of avoiding death (Mair, 1967; Rozovsky, 1974). This hope, coupled with the emotional and practical difficulties of caring for dying persons, contributed to the emergence of an avoidance-of-death phenomenon (Wallace, 1951). No longer was death anticipated or acknowledged. This phenomenon became the norm among physicians and nurses, whose education was now oriented to saving lives (Lindabury, 1969). It was not until 1969 that Elizabeth Kubler-Ross defined this as inappropriate treatment and advocated for open discussion of dying and death.

All of these developments meant that alternatives to hospital-based care either were not developed or became less available. In short, palliative care was not recognized as an option in the excitement generated by many life-saving developments within the hospital setting. Expert care in accessible, high-quality hospitals had become more desirable than care in the home.

Initiation of Palliative-Care Era (1970–89)

Numerous health and social developments in the 1970s and 1980s reinforced the hospitalization-of-death trend. One of the most significant was a steady increase in the number of hospital beds (Health Canada, 1996). Developments in hospital technology also continued, particularly for cardiovascular surgery, organ transplantation, and drug therapy (Nicholls, Jung, & Davies, 1981), all enormous strides in preserving and extending life. More highly educated nurses, physicians, and other health professionals also strove for higher quality care. The rising employment of women (McVey & Kalbach, 1995) continued to reduce the possibilities for family caregiving in the home (Siebold, 1992).

However, the health system also began to be criticized as hospital-based and cure-oriented (Vayda & Deber, 1984). The need for disease prevention and health promotion became evident (Canadian Nurses Association, 1980; LaLonde, 1974). The cost of the health system as a result of the 1970s recession was also problematic. Governments actively sought ways to reduce spending, and health care was not exempt. The *Established Programs Financing Act* of 1977 was the first of many federal acts aimed at reducing Ottawa's share of health spending by the provinces (Vayda & Deber). Yet public funding for health promotion, long-term care, and home care was increased (Adams, 1989; Clarfield, 1983). For example, in 1977 the federal government initiated the Extended Health Care Services for Long Term Care program to enable provinces to provide more home care and long-term institutional care (Soderstrom, 1978). These changes were directed at reducing hospital use by elderly people, as research was demonstrating an ageing of the population and extensive use of the hospital system by the elderly (Roos, Montgomery, & Roos, 1987; Shapiro, 1983).

Another health-care issue became evident: an inability to treat all illnesses successfully (Hale, 1989). The most problematic issue was the ability to save a life while prolonging the dying process, as reflected in abundant literature on withdrawing and withholding treatment; the economic, personal, and social costs of aggressive cure-oriented but largely futile treatment; and the need for reform in the areas of consent, decision-making control, and information-sharing by physicians. Legal, social, and health-care advances ensued. These included: a patient rights statement (Consumers' Association of Canada, 1972), informed consent guidelines (Ferguson, 1980), brain-death criteria (Ellis, 1990; Walton, 1980), hospital do-not-resuscitate policies (Wallace, 1975), and the *Joint Statement on Terminal Illness* (1984). The *Joint Statement* made it clear to health professionals that they need not provide futile treatment to dying persons.

Not surprisingly, given this contextual background, palliative care was formally introduced. In 1975–76, palliative-care units were established in two acute-care hospitals (Mount, 1976), and these became the model for palliative treatment in Canada (Heidemann, 1984; Siebold, 1992). Because it was situated in hospitals, however — with their socially accepted and culturally based mandate to diagnose and cure — palliative care became subject to competition for recognition and funding (Ajemian, 1992; Latimer, 1991; Priest, 1987).

Palliative care was also confounded by the 1970s recession. Funding cutbacks, first by the federal government and then by the provinces, led to a shift of care to the home. Concerns about informal caregiving quickly surfaced (Brown, Potter, & Foster, 1990). Whereas home care had just recently been the norm, informal caregiver burden was now considered a serious individual and social problem (Brown et al.).

Other challenges to palliative care were evident, chief among them the fact that dying in hospital was commonplace, if not standard. Another challenge was the public perception that premature death is largely preventable (Vachon, Kristjanson, & Higginson, 1995). Palliative care will understandably be resisted if a cure is considered likely. In short, although hospitals began to provide specialized palliative care in this era, death in hospital often occurred after cure-oriented hospital treatment failed to sustain life (Ajemian, 1992; Siebold, 1992). Furthermore, terminally ill persons died in hospital as this was the pre-ferred place, if not the only possible place, for end-of-life care.

Contemporary Era (the 1990s)

The 1990s brought even more severe economic pressures and, with them, rising concern about hospital inefficiency. This concern is illus-trated by numerous studies showing the widespread use of hospitals for sub-acute and non-acute care (Decoster, Roos, & Carriere, 1997; Doyle, Barrett, McDonald, McGrath, & Parfrey, 1998; Flintoff et al., 1998; Hospital Services Utilization Review Commission, 1994; Hunter, 1997; Joint Policy and Planning Committee, 1997; Kaplow, Charest, & Benaroya, 1998; Mayo, Wood-Dauphinee, Gayton, & Scott, 1997). Many of these studies report elderly persons to be high users of hospitals, a distinct issue given an ageing population.

Furthermore, and despite considerable advances in palliative care (Mount, Scott, & Cohen, 1993), concerns were raised about use of the hospital as a place of death (Ajemian, 1992; Latimer, 1991; National Forum on Health, 1997; Novak, 1997). Concerns included the issue of dying among strangers, the use of life-supporting technologies during the last days of life, and undertreated pain (Lavis & Anderson, 1996; Litwin & Lightman, 1996; National Forum on Health; Roos, Montgomery, & Roos, 1987; Stokes & Lindsay, 1996; Wilson, 1997).

Alternatives to inpatient care were now possible as a result of advances in drug therapies and diagnostic and surgical technologies (Clarkson, 1993; Dudgeon & Kristjanson, 1995; Landesman, 1996;

Macnaughton, 1992; National Forum on Health, 1997). There was a shift to day surgery and outpatient care, shorter hospital stays, and community-based programs (National Forum on Health; Tully & Saint-Pierre, 1997).

The 1990s also saw the initiation and growth of non-hospital palliative-care programs (Canadian Palliative Care Association, 1997; Health Canada Working Group, 1997). Some of these were non-government, as in the case of free-standing hospices (Davies, Eng, Arcand, Collins, & Bhanji, 1996; Feser, 1992), small and oriented to the care of persons with a particular illness such as AIDS. Most were provincial home-care programs that did not cover the full cost of home supports, medications, and nursing (Canadian Palliative Care Association). No national program emerged to ensure the availability of palliative-care services across Canada (Muzzin, Anderson, Figueredo, & Gudelis, 1994).

The 1990s shift to largely unsupported home care was viewed as problematic in that it added to existing concerns about the ability of families to provide care. Home care had also become more challenging, as informal caregivers were expected to provide many of the treatments that had previously been provided in hospital. Research was finding barriers to the provision of home-based terminal care: smaller nuclear families, the anguish of providing terminal care for loved ones, and personal financial difficulties (loss of income, career interruption, reduced pension) (Chochinov & Kristjanson, 1998; Coyle, 1997; Dudgeon & Kristjanson, 1995; Gomas, 1993; Grande, Addington-Hall, & Todd, 1998; Hagen & Gallagher, 1996; Hinton, 1994a, 1994b; Hull, 1991; McWhinney, Bass, & Orr, 1994; Myles, 1991; Pugh, 1996; Townsend et al., 1990). Many other barriers to home-based care were also evident, such as physician fee-for-service systems that did not support home visits (Latimer, 1995). The shift to home care affected mainly women, as women were now clearly recognized as the chief informal care providers (Angus, 1994; Baines, Evans, & Neysmith, 1991; McDaniel, 1992; Ross, 1991; Wuest, 1993).

The 1990s also saw increased interest in natural or technology-free death (MacDonald, 1991), perhaps in reaction to the persistence of active treatment late in the dying process (Lindsay, 1991; Wilson, 1997), infrequent referral to palliative-care specialists (Hooper, 1991), and the continued emphasis on life-saving procedures in the education of doctors and nurses (Ajemian, 1992; Bruera, Selmser, Pereira, & Brenneis, 1997; Kristjanson & Balneaves, 1995; Marshall, Hutchison, Latimer, & Faught, 1997). As some terminally ill persons were avoiding

hospitals because of the technology housed there (Tolle, Rosenfeld, Tilden, & Park, 1999), the desire for a natural death outside of the hospital can be seen as a major new influence on location of death.

Regardless, home deaths still occurred only among those people who had come to accept a need for comfort-only care (Grande et al., 1998; McWhinney et al., 1995; Townsend et al., 1990). At the same time, research was finding that cardiopulmonary resuscitation was rarely used in Canadian hospitals and continuing-care facilities after it had been determined that nothing further could be done to preserve life (Wilson, 1997) — an indication that natural death could take place in hospital as well as elsewhere.

Public demand for information and control was another significant development of the 1990s (Calder, 1994; Davies, 1996; Fakhoury, McCarthy, & Addington-Hall, 1996; Keizer & Kozak, 1992; Sneiderman, 1993). Interest in assisted suicide (Elash, 1997), advance directives (living wills) (Singer, 1994), and alternative health care (Astin, 1998) is further evidence of changing public needs and expectations. Advance-directive laws (Singer), palliative-care guidelines for health professionals (Canadian Medical Association, 1992), and clear recognition of and strong support for palliative care (Mykitiuk & Paltiel, 1994; National Forum on Health, 1997; Senate of Canada, 1995; van Weel, 1995) are some of the key outcomes of these changing needs and expectations.

In summary, the extensive use of hospitals by dying persons throughout the 1990s indicates that many health-care and social influences continued to favour hospitals as the prime location of death. However, some major developments in non-hospital palliative-care programs and beliefs about death and dying were evident in the 1990s, and these influenced location of death in that they supported a shift of care from the hospital to other locations.

Conclusion

This multidisciplinary historical investigation identified two key influences, among many, on location of death in Canada. One key influence was health-care and health-system developments that consolidated health care in hospitals while at the same time raising and sustaining public expectations about curative or least beneficial hospital care. The rising hospital death rate throughout much of the 20th century can thus largely be considered an outcome of the shift in illness care from the home to the hospital. The other key influence on location of death was the reduced availability of home-based formal and informal caregivers.

This report has identified a number of discrete developments that limited the possibility of end-of-life caregiving in the home. Chief among these were the increased participation of women in the workforce, the shift in nursing work from private home duty to hospitals, and a shift in medical care to hospitals, clinics, and physicians' offices. Although the 1990s witnessed the development of some health and social support for caregiving in the home, this clearly did not match the health and social support for hospital-based care.

These findings indicate that location of death is an important focal point for studying and planning improvements in end-of-life care. The recent reduction in the number of hospital deaths, after a shift of death to the hospital setting during much of the 20th century, indicates that this is an opportune time for nurses and others to research and address issues in end-of-life care. On a final note, this study shows that the health system and health care both shape and are shaped by the needs and expectations of the public.

Appendix 1 *Research Plan*

Nurse: search for nursing, health policy, and law information in CINAHL, HealthSTAR, Canadian Research Index/Canadian Government Documents, CANSIM, and Index to Legal Periodicals and Books.

Palliative-care physician: search for medical, pharmacological, and health-care technology information in Medline, EMBASE, and Cancerlit.

Health-care historian: search for historical information on vulnerable/ disadvantaged populations, including children, women, and immigrants, in Histline and America: History and Life (this database includes Canadian historical literature).

Nurse gerontologist/psychologist: search for psychology and gerontology/ ageing information in PsychINGO and Social Studies Abstracts.

Philosopher/ethicist: search for philosophy, religious studies, and ethics information in Humanities Abstracts and Philosophers Index.

Sociologist: search for sociology, political science, and business/economics information in SocLit, EconLit, ABI Inform, and Canadian Business and Current Affairs.

All researchers began their search using the following key words: death, dying, palliative care, terminal care, end-of-life care, hospital, home care, health system, location of death, Canadian, and Canada. The search was initially limited to the distinct years of each historical era, then expanded as the researcher sought extensive and diverse sources of information.

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Authors' Note

The *CJNR* Editorial Board has modified the Journal's publication schedule so that each volume will fall within the calendar year. The Journal will continue to be published on a quarterly basis. Beginning in 2003, issue no. 1 will be published in March, followed by issues 2, 3, and 4 in June, September, and December. Due to this change, we are able to grant an extension on several expired deadlines for calls for papers.

CJNR Special Issue:
Completed Student Research Projects
December 2002 (vol. 34, no. 4)

The December 2002 issue of *CJNR* will highlight the work of the next generation of researchers. Papers describing completed research from either undergraduate or master's programs (i.e., excluding doctoral programs) are being sought. We are interested in reports of studies that have used one or more of a variety of methodologies to examine clinical or other areas of nursing meant to advance knowledge in the field. Manuscripts should be no more than 10 pages, double-spaced, 12-pitch type, including references, tables, and figures. Since all papers will be subject to an expedited peer-review process, a paper's chances of being accepted will be improved if it has been reviewed and edited by someone with authorship experience, and revisions made accordingly, prior to submission. Prizes of a one-year complimentary subscription to *CJNR* will be awarded to the students with the three strongest papers.

The *CJNR* Editorial Board realizes that many student projects have not received formal IRB approval. Nonetheless, every study must meet accepted standards of ethical conduct. A number of procedures must be followed to ensure the ethical integrity of the study with regard to the treatment of human subjects. Authors are asked to include in their manuscripts a paragraph outlining the procedures that were followed to ensure the ethical integrity of the study.

Submission Deadline: October 1, 2002

Addiction & Dependence
March 2003 (vol. 35, no. 1)

In nursing and in other disciplines, addiction, dependence, and addictive behaviours and their health consequences are of growing social concern. This issue will focus on all aspects of these phenomena as they intersect with nursing practice in all health-care settings. We are interested in addiction in all its forms (e.g., tobacco, drugs, alcohol), any behaviour that results in a physiological dependency (e.g., eating disorders), the effects on individual and family well-being across the lifespan, physical and mental health outcomes, and prevention and intervention. We are also interested in individual, parental/family, and social/environmental factors that place individuals at risk or that lessen the risk of these phenomena. We are particularly interested in the testing of interventions and the factors that contribute to an intervention's success. We plan to mainly publish research reports but will consider papers on theory development and testing. We welcome investigations that use either qualitative or quantitative data or a combination of the two.

Guest Editor: Dr. Pamela Ratner
Submission Deadline: *extended to* **October 15, 2002**

Culture & Gender
June 2003 (vol. 35, no. 2)

Culture and gender have been identified as important determinants of health. For this issue, we invite papers that examine the interaction of culture and gender with other health determinants, and the influence of culture and gender on the outcomes of nursing interventions. Manuscripts that describe research studies, present a systematic review, or provide a theoretical analysis will be considered. We are particularly interested in papers that focus on innovative interventions designed to mediate the influence of culture or gender on collective health action, individual behaviour change, social environments, health-service utilization, or health status. We welcome papers describing studies undertaken either in Canada or internationally.

Guest Editors: Dr. Nancy Edwards and Dr. Judy Mill
Submission Deadline: *extended to* **November 15, 2002**

Nursing Care Effectiveness
September 2003 (vol. 35, no. 3)

In the context of the changes that are currently taking place in health-care systems, it is imperative that the effectiveness of nursing care be systemically studied and highlighted in research reports. Additionally, it is critical that the policy implications of such research be specifically addressed. For this issue of the Journal, we invite papers that examine nursing care effectiveness in terms of health outcomes for individuals, families, groups, communities, or populations and from the perspective of the cost to clients and to health-care systems. We will consider manuscripts that describe research studies, present a systematic review, discuss the implications of nursing care effectiveness research on policy, present methodological issues, or provide analysis of theoretical and/or ethical issues.

Guest Editor: Dr. Sandra M. LeFort
Submission Deadline: *extended to* January 15, 2003

Gerontology
December 2003 (vol. 35, no. 4)

As populations age, all disciplines and public-service sectors are beginning to address the issues of ageing from their diverse perspectives. For this issue of *CJNR* we invite manuscripts that present research focused on enhancing the health and life of older populations through the creation and dissemination of knowledge relevant to gerontological nursing practice and the policy, health-services delivery, and practice issues germane to optimizing the health and lives of older people. We particularly welcome papers on innovative interventions and strategies for promoting health and well-being in later life.

Guest Editor: Dr. Carol L. McWilliam
Submission Deadline: April 15, 2003

Please send manuscripts to:
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CJNR 2000–2004:
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Publication date: September 2000

Chronicity
Submission deadline: April 30, 2000
Publication date: December 2000

Abuse & Violence
Submission deadline: July 30, 2000
Publication date: March 2001

VOLUME 33

Economics of Nursing Care
Submission deadline: October 15, 2000
Publication date: June 2001

Home Care
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Addiction & Dependence
Submission deadline: *extended to* October 15, 2002
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Culture & Gender
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Information for Authors

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

Procedure: 1. Articles must be written in English. 2. Authors are requested *not* to put their name in the body of the text, which will be submitted for blind review. 3. Only unpublished manuscripts are accepted. 4. All research studies must have received IRB approval. 5. A written statement assigning copyright of the manuscript to the *CJNR* must accompany all submissions to the Journal. 6. Manuscripts should be submitted by e-mail to the Editor, c/o joanna.toti@mcgill.ca

Manuscripts

Manuscripts must be prepared in accordance with the Fifth Edition of the *Publication Manual of the American Psychological Association*. Research articles must follow APA style for presentation of the literature review, research questions and hypotheses, method, and discussion. All articles must adhere to APA guidelines for references, tables, and figures. Footnotes are to be avoided.

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

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Renseignements à l'intention des auteurs

La revue *CJNR* est publiée quatre fois par année. Son mandat premier est de diffuser les travaux de recherche axés sur le développement des connaissances et leur mise en pratique au sein de la discipline des sciences infirmières. La revue accepte également les articles de recherche traitant d'éducation et d'histoire, ainsi que les articles sur la méthodologie, la théorie et l'analyse critique qui contribuent à l'avancement des sciences infirmières. Les lecteurs et lectrices sont invités à faire parvenir leurs commentaires sur les articles publiés dans la revue.

Modalités : 1. Les articles doivent être rédigés en anglais. 2. Pour garantir l'anonymat des auteurs pendant l'examen des articles, on demande à ceux-ci d'éviter d'indiquer leurs noms dans le corps du texte. 3. Seuls les manuscrits inédits seront acceptés. 4. Tous les projets de recherche doivent avoir reçu l'approbation d'un comité d'éthique. 5. Une déclaration de cession du droit d'auteur à la revue *CJNR* doit accompagner toutes les propositions d'article. 6. Les manuscrits doivent être soumis par courriel à la rédactrice en chef a/s: joanna.toti@mcgill.ca.

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