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EDITORIAL

A Matter of Choices

Being the editor of a nursing research journal requires one to be both reactive and visionary, but the former is the greater requirement by far. Topics for each focus issue are selected 5 years in advance. Some topics are selected because we know they have and will continue to have a profound impact on nursing and patient care. Others are barely perceptible issues when we begin the planning process but are predicted to become of major importance to society and hence to nursing science.

Choosing to devote an issue of *CJNR* to the economics of nursing was a "no-brainer." This was not a "visionary" decision. We were reacting to the major force that had been driving nursing and health-care decisions for a decade. When we made the choice, nursing was in the midst of absorbing the effects of downsizing. Although nurses and nursing were invisible, in many ways, in the decision-making arenas, the cost of nursing was highly visible in health-care budgets and could not be easily ignored. Nursing budgets were drastically slashed without thought to or understanding of the effect of the cuts on the nursing workforce, health-care services, or patient care. Many believed that the cuts were a way of holding nursing accountable. Nursing leaders welcomed the opportunity to demonstrate nursing's significant contribution to society — this time, however, with a price tag attached. Granting agencies encouraged applicants to include an economic analysis. When we scheduled this issue, therefore, we believed there would be a proliferation of studies eager to report their findings on the economic costs of nursing, and we invited Dr. Gina Browne to serve as the guest editor.

Gina was an obvious choice, an easy choice. I have known Gina since the mid-1970s when Canadian nursing research was in its infancy and we were the "new kids on the block" — mere babes. Even in those early years, we all knew Gina would make a profound difference. She was a visionary, not just sensing trends but creating them. Gina was also a mover — she thought "big," knew how to get things done, and knew how to envision a problem beyond the confines of nursing.

Almost a decade ago I was intrigued to learn about the establishment of the Systems-Linked Research Unit on Health and Social Services Utilization at McMaster University, a unit developed to evaluate models of care and their ability to meet the needs of the vulnerable,

the heavy users of the health-care system. It was an innovative idea, breathtaking in its scope and ambition. I was not surprised to learn that Gina was its founder and director. She and her team had the foresight to "cost out" health-care utilization long before the dollar sign became predominant in health-care decision-making. Thus Gina had not only the requisite specialized knowledge and expertise to be a guest editor, but also the credibility and connections within and outside of nursing to assemble this important focus issue.

Given the timeliness and importance of the topic, we expected to be deluged with manuscripts. Experience has taught us that we need to review at least 12 manuscripts in order to select four that reflect the range and depth of the field being featured. You can imagine our surprise when the deluge failed to materialize and we received only three submissions, one of which came from the McMaster unit. It was unclear why there were so few.

After some investigation and reflection, the answer became obvious. Although the nursing scientific community and the nursing administrative community place high value on costing the effectiveness of nursing care, in reality few nurse-scientists had included a cost analysis in their grant applications, and those who had — these notable exceptions are outlined by Sochalski in the Discourse — did not have the data ready for publication. We were faced with a dilemma. We could either cancel the issue or put one together relying heavily on the expertise and research of the McMaster Systems-Linked Research Unit. Gina and I debated the pros and cons, but in the end it was I, as *CJNR* editor, who decided that the topic was too important, too timely, to postpone; there was much to be learned from the few pioneers in the field.

Gina and I worked closely together to build an issue that would maintain the Journal's integrity and high standards. Gina stepped aside when it came to submissions from the Systems-Linked Research Unit team. All unsolicited manuscripts were blind, peer-reviewed. As with other focus issues, we invited scholars in the field to write the Discourse and Designer's Corner. We also departed from convention by creating a new section, called Translating Research. An important aspect of a research program is deciding when to disseminate the findings and when to make them understandable to a larger audience. After 10 years of accumulated evidence, Gina's team is at this stage. We created a new section to feature their work, and this section will be another standard feature of *CJNR*, appearing from time to time.

The take-home lesson taught to me by Gina is that economics is not about dollars — yes, dollars are involved, but *economics is really about choice,* how we use resources when faced with competing alternatives. It is a recurrent, underlying theme of every article in this focus issue. Rodney and Varcoe argue for the importance of conducting ethical inquiry concomitantly with economic inquiry if we are to make choices that are in the best interest of the public. They point out that value clarification is critical in making "good" choices — which are not always the least expensive ones. Roberts and her colleagues costed out different types of postpartum services to different groups of mothers. Although a few mothers "cost" the system more, it may be that the provision of early detection and treatment will actually translate into enormous savings in the long-term health of both mother and infant. In the Discourse, Sochalski asks two fundamental questions — namely, how many resources need to be allocated to nursing to create and maintain a well-qualified and effective nursing force, and how should these resources be allocated to most effectively meet the evolving health-care needs of the public. An economic framework is needed to address these questions and to outline the different choices available. Gafni, in Designer's Corner, provides an insightful analysis of the construct of willingness-to-pay and its measurement. This important construct will only gain in significance as the public and policy-makers decide who will foot the bill, and for what aspects of health-care services. Browne and her colleagues are at an enviable point in their research program. After conducting 12 well-controlled randomized trials, asking basically the same questions and using the same measures but with different populations, they have arrived at patterns of findings that are robust as to drive policy. They have translated their findings into language that is comprehensible to policy-makers and the public. Finally, Guerriere and Murphy, in Happenings, cite much promising work on the economics of home care that is now underway in Canada.

This issue of the Journal is about choices and choosing. In choosing to publish this issue devoted to nursing economics, we hope that the word *economics* will conjure up new images and stimulate new ways of making ethical choices in the best interest of the public.

Laurie N. Gottlieb
Editor

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Commentary

Countering the Deterioration and Medicalization of Nursing

June F. Kikuchi

In light of Laurie Gottlieb's (2000) insightful editorial, "Shortage of Nurses, Shortage of Nursing," I thought it might be worthwhile to bring readers' attention to related editorials which have recently appeared in nursing journals published in other countries. These indicate that the growing deterioration and medicalization of nursing is an international problem requiring international solutions.

Gottlieb, editor of the *Canadian Journal of Nursing Research,* correctly asserts that it is simplistic to attribute the deteriorating quality of nursing care solely to a shortage of nurses. She states that there are other reasons we must consider, reasons which are

> embedded in nursing education; in the lack of a clear vision and framework for nursing; in an attitude on the part of nurses, their leaders, and others that devalues nursing activities and over-values medical activities; and in the resource-allocation choices of nursing leaders, front-line nurses, and others. (2000, p. 3)

Helen Scott (1999, 2000a), editor of the *British Journal of Nursing,* is concerned that the current lack of fundamental nursing care will only worsen with the continued delegation of nursing duties to non-nursing personnel as nurses take on more and more medical tasks. She pleads with nurses not to stand by and let others change the practice of nursing to suit their vested interests, to speak out against government plans to train nurses to perform endoscopies, prescribe medications, order diagnostic tests, and so forth in order to decrease doctors' workloads. "What is clear is that the Government thinks that in order to be considered 'smart', nurses need to take on doctors' roles," states Scott (2000a). In another editorial (2000b), she observes that the "medical specialization of nursing seems to be now almost inevitable" and expresses concern that

> the Government's vision for nursing seems to be supported by the RCN [Royal College of Nursing], which claims that: the patient is better served if nurses are able to carry out technical tasks such as endoscopies, as this increases continuity of care; research shows that nurses are just as effective as doctors when carrying out medical roles; and expanding the nursing role to incorporate medical activities will encourage nurses to stay in nursing.

Peggy Chinn (2001), editor of *Advances in Nursing Science,* expresses alarm at the growing trend, in American nursing education programs, to eliminate nursing theory courses to the point where even those programs in which nursing theory had been fully incorporated are being dismantled and replaced with medically oriented ones. She writes:

> Basic professional nursing and especially advanced practice nursing have reverted all too often, in my view, to the very handmaiden roles that we delude ourselves into thinking that we escaped.... The terms we use to describe many nursing roles sound more autonomous and sophisticated, but the fundamental truth is that much of what nurses do, and where they place their priorities, is nothing more than serving another discipline's goal and interests, not our own. (p. v)

Chinn does not object to nurses' taking on skills which have resided solely within the domain of doctoring, but she does object to their doing so at the expense of nursing.

Reading these editorials, I was struck by the fact that, essentially, the editors are implying that nurses are contributing, in one way or another, to the growing deterioration and medicalization of the profession. By failing to clearly define nursing, for example, nurses have left it wide open for others (including those nurses who do not like nor value nursing yet remain in the profession) to change nursing to their own liking. Gottlieb (2000) speaks of "the lack of a clear vision and framework for nursing" (p. 3). Scott (1998) asserts that "time and energy should be put into defining what the essence and value of nursing has been in the past. It is this essence and value which must be used to create a modern definition of nursing." Chinn (2001) states, "It is time for nursing faculty to seriously examine our essential focus.... It is time to consider how much longer we will allow our educational enterprise to be charted by interests other than our own" (p. v).

What these editors are saying is not new. For decades, nursing leaders have been warning that a clear definition of nursing is essential to guide nursing endeavours and prevent the erosion of the profession. Well, the erosion is underway. Nurses can no longer ignore the need for members of the profession to come together and work towards enunci-

ating a definition of nursing that is clear, understandable, comprehensive, and acceptable to the majority of nurses. The erosion will not be stopped solely by defining the nature of nursing, but it *cannot* be stopped without defining the nature of nursing.

The question *what is nursing?* is a philosophical one and can only be addressed by philosophizing. The inquiry must include nurses who are or have been actively engaged in nursing practice, are devoted to and value nursing, and do not aspire to become mini doctors, mini psychologists, mini ministers, and so forth. With the help of similarly qualified nurse philosophers, they can work towards enunciating a sound definition or philosophy of nursing and thus establishing a basis for determining whether various activities fall within the realm of nursing.

By philosophizing, we may discover, for example, that an area of nursing responsibility is encouraging patients to maintain nutrition and hydration and that activities such as identifying, prescribing, and administering medications to promote the healing of mouth ulcers, so that patients can eat and drink in comfort, are part and parcel of that responsibility. Of course, such possibilities depend on our enunciating a sound philosophy of nursing and, therein, identifying nursing's areas of responsibility. That is no easy task. Collaborative discussion and analysis of ideas take time, energy, patience, and commitment. But I think nurses are up to the challenge. With the guidance of not only nurse philosophers but also nurse historians — for in order to plan our future we must understand our past — nurses can get the job done. What we require is the desire and will.

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Discourse

Nursing's Valued Resources: Critical Issues in Economics and Nursing Care

Julie Sochalski

Nursing's first steps into the 21st century have been charted by a set of pressing economic issues around the composition and allocation of nursing resources. Buffeted by a deepening nursing shortage of global dimensions, health-care demand that is outpacing resources, and consumer demands for safe, effective, and responsive care, nursing finds itself at a critical juncture regarding two fundamental questions: what resources (financial and other) are necessary to build and maintain a qualified and effective nursing workforce, and how can nursing resources be most effectively allocated to meet evolving health-care needs. The current plight provides us with an opportunity to address such questions in new and creative ways, by critically examining how we are supporting the current nursing workforce and preparing the future one, the settings and roles in which the workforce is deployed, and the degree to which decisions in these matters are based on research that demonstrates the most cost-effective ways of allocating nursing care. The aggressive pursuit of these questions requires the input of every branch of the profession: practice, administration, education, research, and policy. It also requires that we grapple with the following issues.

First, nursing finds itself once again battling a workforce shortage. Though the causes may vary, this shortage has serious implications for the kind of nursing care we are able to provide and for how well current and future health-care needs will be met. While we have stared down previous nursing shortages, largely through short-term financial

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solutions, many argue that the current shortage is more ominous. A depressed pipeline of new entrants is colliding with an aging workforce, suggesting a much smaller workforce in the future, if no substantial effort is made to change the course of events (Buchan, 1999; Buerhaus, Staiger, & Auerbach, 2000). If the contracted workforce were coupled with a decline in demand for nursing services, there would not be cause for great concern. But there are no signs that demand is abating. Nurses have been and continue to be employed in record numbers. Furthermore, as the nursing population ages so does the general population. The demand for services is consequently rising, for acute as well as chronic care. The burden is falling squarely on the shoulders of all care providers but especially nurses. The multi-faceted needs and complex regimens of elders and the chronically ill require heightened levels of coordination and monitoring that are central to the role of nursing. Carrying out this work without the necessary resources and organization has become an enduring struggle and is causing the system to fray. Early discharge from acute-care facilities has strained the post-acute-care system, where the delivery of essential care and the coordination of services across far-flung providers and agencies/settings are overwhelming the system. Those considering nursing as a career and those among the ranks of practising nurses are looking at this state of affairs and having second thoughts about the profession.

Evidence from both Canada and the United States underscores the predicament. According to the Canadian Institute for Health Information, the RN-to-population ratio in Canada fell from 80.3 to 74.6 RNs per 10,000 population between 1994 and 1999 (Canadian Institute for Health Information [CIHI], 2000). This change was the result of a 2.5% decline in the number of practising RNs and a simultaneous increase in the population over the period. In the US, where data on the workforce are collected quadrennially through a national sample survey of RNs, the 1996 ratio, at 79.8 RNs per 10,000 population, was comparable to Canada's 1994 figure (Moses, 1996). By 2000 the US ratio was also beginning a descent, to 78.2 (Division of Nursing, 2001), due to a much slower rate of growth in practising RNs than in the population. At 4.1%, the growth rate in practising RNs between 1996 and 2000 in the US was the lowest recorded since 1977 when the sample surveys started collecting this information (Division of Nursing).

In both Canada and the US, nursing care is increasingly moving out of the hospital and into the community (Sochalski, Aiken, & Fagin, 1997). In Canada, the proportion of RNs working in hospitals declined from 61.1 to 59.4% between 1994 and 1999. This was a result of not only a growth in the number of RNs in other sectors but also a 5.5% decline

in the absolute number of nurses reporting to work in a hospital (CIHI, 2000). After hovering near 70% since 1984, the proportion of RNs in hospitals in the US fell to 60.1% in 1996 and to 59% in 2000 (Division of Nursing, 2001; Moses, 1996). Not only did the proportion of hospital nurses decline, but the absolute number of inpatient bedside nurses fell, by 6.2% in 1996 and by another 8.5% in 2000. The proportion of total health expenditures devoted to hospitals has similarly declined in the two countries. In Canada, hospital spending fell from 45.2% of total spending in 1976 to 32.2% in 1999 (CIHI, 2001). In the US, the hospital portion of total health expenditures decreased from 42% in 1980 to 32% in 1999 (Heffler et al., 2001).

While one would expect that as patient care moves out of hospitals to alternative settings so too will nursing expenditures, one wonders if the exodus of nurses from hospitals is occurring at a disproportionately greater pace, and for reasons other than the transfer of patient care to other sites. Widespread reports from nurses of stressful and unsafe working conditions in hospitals in both countries suggest that this question is worth investigating (Buerhaus & Needleman, 2000; Kaiser Family Foundation and Harvard School of Public Health, 1999; Shindul-Rothschild & Duffy, 1996). A recent five-country study of nursing staffing and patient outcomes in hospitals surveyed thousands of hospital staff nurses (Sochalski & Aiken, 1999; Sochalski, Estabrooks, & Humphrey, 1999). Of the Canadian nurses surveyed, fully one third reported dissatisfaction with their current job, more than one third reported significant levels of job burnout, and nearly half reported that the quality of nursing care in their hospital had declined over the preceding year (Aiken et al., 2001). Among US nurses, levels of job dissatisfaction and burnout were even higher, at 41% and 43%, respectively, and comparable numbers reported declining quality of nursing care in their hospital. In each country nearly one third of nurses under age 30 indicated they intended to leave their nursing job within the year. These findings suggest that, without attention to the role of nurses and the working environment in hospitals and other health-care settings, efforts to address the shortage by increasing the supply of nurses in these settings will do little to ameliorate the situation.

Although the nursing shortage has certainly raised the profile of economic issues in nursing, it represents only one half of the economic equation. Characterizing the shortage brings into focus the second part of nursing's economic agenda — amassing and applying the evidence of effective nursing practice. Jenkins-Clarke's (1999) excellent treatise on economic evaluations in nursing starkly reminds us of the distance we need to travel with regard to assessing which nursing interventions,

and what mix of nursing personnel, are needed to achieve the desired outcomes in patient health. A number of barriers have stood in the way of further development in this area. These include inadequate application of cost-effectiveness methodologies, inconsistent and/or incomplete cost-effectiveness measures, and lack of robust outcome measures (Allred, Arford, Mauldin, & Goodwin, 1998; Bond & Thomas, 1991; Newbold, 1995; Tierney, 1993). Indeed, the development of suitable outcome measures to distil the effect of nursing in an economic evaluation continues to be a challenge, given the interdisciplinary nature of and multiple inputs into patient care in most settings. Intermediate outcome measures, such as those that capture quality of care, are one approach to such evaluations (Sochalski, 2001). However, the relationship among cost, quality of care, and outcomes is complex, and care must be taken regarding the measures that are used and the causal effects being asserted (Jenkins-Clarke). For example, total nursing costs per patient may have a modest relationship with incidence of skin breakdown and pressure ulcers, but cost per hour of nursing care can have a pronounced effect on length of stay, an outcome that theoretically will be influenced by the occurrence of pressure ulcers. The conclusions one might draw about the relationship among quality of care (occurrence of pressure ulcers), outcomes (length of stay), and cost (workload hours) could vary greatly depending on the measures used and the causal direction modelled in the analysis.

Galvanized by the increasing demand for answers within and outside of nursing, economic evaluations of nursing have become more frequent over the last decade, and have expanded into many clinical settings and across various types of patients and care needs. Single-site and multi-site studies evaluating the cost-effectiveness of nursing interventions, some employing randomized controlled trial designs, can be found with increasing frequency in the literature (Helgessen et al., 2000; Kitzman et al., 2000; Mandelblatt et al., 1997; Naylor et al., 1999; Stewart, Pearson, Luke, & Horowitz, 1998; Uhari & Mottonen, 1999). These empirically robust studies are offering evidence of innovative and cost-effective ways of using nurses across the continuum of care. One area of considerable development going back several decades has been nurse-physician substitution in primary-care and other settings (Brown & Grimes, 1995; Mundinger et al., 2000; Prescott, 1994; Richardson, Maynard, Cullum, & Kindig, 1998). While many of these studies show that the quality of nursing care is equivalent to or surpasses physician care, with few exceptions they are dated and lacking in rigorous cost analysis (Jenkins-Clarke, 1999; Richardson et al.).

So, despite progress in this area, the reservoir of studies that include economic evaluations of nursing care is still quite low and is plagued by many problems. Moreover, our collective understanding of what works, and at what cost, has been hampered by the absence of a method for amassing the information and assessing its gaps. These deficiencies can and should be addressed. Nursing is well positioned to launch a concerted effort to evaluate its care, one that develops both theoretical approaches and a robust set of outcome measures to assess interventions, and that applies the full array of cost-effectiveness methodologies and analytic tools. Collaboration with other disciplines such as economics, public health, and health services research would enhance not only the investigations themselves but nursing's accountability regarding the allocation of its resources in the pursuit of public-health improvements. Amassing the evidence of cost-effective practice around key clinical areas and nursing workload, and assessing the knowledge gaps, might be stimulated by establishing new study areas through entities like the Cochrane Collaboration. For example, investigation protocols have been established under the Cochrane Collaboration on the substitution of nurses for physicians in primary care (Laurant, Sergison, & Sibbald, 2001) and on organizational infrastructures to promote evidence-based nursing practice (Foxcroft, Cole, Fulbrook, Johnston, & Stevens, 2001). By both initiating and participating in such interdisciplinary forums, we will be able to disburse the evidence of cost-effective nursing practice to a wider audience and direct our nursing resources wisely.

However, efforts to establish evidence-based practice that ignore the question of cost, cautions Maynard (1995, 1997), run the risk of endorsing unethical practices — wasting resources on care that while beneficial for an individual is not cost-effective when considered over society as a whole. These are tough questions that must be addressed head-on if health-care resources are to be allocated in ways that are in keeping with both societal and professional goals.

Economics has had the dubious distinction of being termed the "dismal science," and its application in health care has often pitted clinicians against economists in a struggle to lay claim to the mantle of patient advocacy. Practically speaking, economics provides a framework for the allocation of resources, in this case nursing care, among competing ends and the costs, both financial and non-financial, of allocation decisions. The economics question facing nursing is not what the value of nursing care *is* (i.e., costing out nursing services for the sake of determining its costs) but *how* to allocate this valuable resource to best meet the health-care needs of our patients and the population. The goal

is to ensure that the resources allocated to nursing are sufficient and directed towards building a high-quality workforce deployed in the most effective way possible.

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Costs of Postpartum Care: Examining Associations from the Ontario Mother and Infant Survey

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Une étude menée dans le cadre d'une enquête transversale réalisée auprès de 1250 mères de nourrissons « normaux » a été faite dans le but de répertorier les caractéristiques inhérentes aux mères et aux nourrissons ainsi que les coûts des services de santé et des services sociaux auxquels cette population a recours dans les quatre premières semaines suivant la sortie de l'hôpital, et ce en Ontario, au Canada. Les interviewers ont demandé à chaque mère de répertorier le nombre de fois qu'elle a fait appel à des services pour elle-même et pour son nourrisson. Ces chiffres ont été multipliés par le coût à l'unité pour chacun des services et les données ont été additionnées pour établir le coût total des services utilisés. Bien que le taux de réadmission fût peu élevé (1 % chez les mères, 4 % chez les nourrissons), les coûts liés aux soins hospitaliers et aux soins en salle d'urgence (une moyenne de 194 $ par dyade mère / enfant) constituaient la plus grande part des frais liés

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aux soins de santé. En second venaient les coûts liés aux visites d'un médecin ou d'une sage-femme dont la plupart des mères ont bénéficié (une moyenne de 128 $ par dyade). Les frais médicaux pour les mères dont le revenu était inférieur à 20 000 $ étaient plus élevés que ceux des mères touchant des revenus plus élevés. Les coûts en soins infirmiers communautaires (une moyenne de 86 $ par dyade) étaient plus élevés chez les mères qui avaient elles-mêmes identifié plus de cinq points nécessitant de leur part un apprentissage (p. ex. l'alimentation du nourrisson, les soins au bébé et son comportement, les changements qu'elles vivaient sur le plan émotif, les signes révélant des troubles de santé chez le bébé). Ils étaient aussi plus élevés chez celles qui percevaient leur propre santé comme étant déficiente, celles qui sentaient qu'elles ne bénéficiaient pas d'une aide et d'un soutien adéquat à la maison, celles qui éprouvaient de nombreux signes et symptômes de dépression et celles qui avaient été hospitalisées après l'accouchement pendant 48 heures ou moins. Les frais associés aux visites d'une travailleuse sociale étaient plus élevés pour les mères souffrant de dépression et les mères à faible revenu. Les coûts totaux pour les services de santé et les services sociaux étaient deux fois plus élevés pour les mères qui touchaient un revenu inférieur à 20 000 $ (une moyenne de 788 $ par opposition à 399 $ par dyade) et pour les mères souffrant de dépression clinique (845 $ par opposition à 413 $). Notamment, les coûts associés aux soins infirmiers étaient supérieurs pour les mères affichant un taux de dépression élevé (135 $ par opposition à 81 $).

A cross-sectional survey of 1,250 mothers of "normal" newborn infants was conducted to assess mother and infant characteristics as well as the costs of health and social services used in the first 4 weeks after discharge from hospital in the province of Ontario, Canada. Each mother was asked to recall use of services for herself and her infant. This utilization was multiplied by the unit cost of each service and summed to arrive at the total cost of services used. Although re-admission rates were low (1% for mothers, 4% for infants), costs associated with hospital and emergency room care ($194 on average per mother/infant dyad) accounted for the greatest proportion of total health-care costs. Physician or midwife visits, which were received by almost all mothers, were the next most costly service ($128 on average per dyad). Mothers with incomes under $20,000 had more medical costs than those with higher incomes. Costs of community nursing care ($86 on average per dyad) were higher for mothers with more than 5 self-identified learning needs (e.g., infant feeding, infant care and behaviour, emotional changes in self, signs of illness in infant); perception of their own health as poor; perception of inadequate help and support at home; many signs and symptoms of depression; and postpartum hospital stay of 48 hours or less. Costs for social work visits were higher for mothers with depression and mothers with low incomes. Total health and social service costs were double for mothers with family incomes under $20,000 ($788 vs. $399 on average per dyad) and for mothers with clinical depression ($845 vs. $413). Specifically, nursing care costs were greater for mothers with high depression scores ($135 vs. $81).

Introduction

Early hospital discharge following vaginal delivery has become standard practice in the province of Ontario, Canada. The Canadian Pediatric Society (CPS) and the Society of Obstetricians and Gynecologists of Canada (SOGC) have issued policy statements in support of a flexible length of stay with community follow-up (Fetus and Newborn Committee, 1996). However, the full impact of shortened

stay on health outcomes, service utilization, and post-discharge costs is unknown. Although shorter stays reduce costs associated with routine postpartum care provided in hospital, it is not known if length of stay influences the costs of community-based health and social services. Also of interest is whether specific mother and infant characteristics are related to utilization and hence costs of care in the early postpartum period.

Literature Review

A literature search of MEDLINE and Health Star for the years 1990–2000 inclusive, using the keywords *health care costs* and *postpartum*, yielded no studies from Canada measuring service use and costs for women and infants in the early postpartum period. Some studies were found from the United Kingdom and the United States comparing the effectiveness and costs of different community programs. However, few studies have documented the utilization of community-based health services for women and infants in the immediate postpartum period and the association between utilization and different characteristics of the mother or newborn.

Some postpartum and other studies with different populations have found an association between poverty and increased hospital costs (Glazier, Badley, Gilbert, & Rothman, 2000) and between social support and increased health-care costs (Broadhead, Gehlbach, DeGruy, & Kaplan, 1989). Only one study was found examining the relationship of mother and infant characteristics with costs of health and medical care (visits to clinics, health centres, and physicians) (Hakansson, Cars, Petersson, & Carlsson, 1996). In this Swedish study, the researchers examined important factors in determining infant use of health and medical care during the first 18 months. They found that mothers who were blue-collar workers (a possible indication of lower or middle income) had a greater number of visits.

Some studies from the United States and elsewhere have found no increase in hospital re-admissions after early discharge in low-risk mothers with adequate follow-up (Brumfield, 1998; Edmonson, Stoddard, & Owen, 1997). A British study found the provision of post-natal support by support workers (homemakers) to have no effect on quality of life, depression, social support, breastfeeding rates, or health-care costs at 6 weeks and 6 months after support worker visits (Morrell, Spiby, Stewart, Walters, & Morgan, 2000).

A randomized controlled trial in the United States examined the effect of an early-discharge home follow-up program for low-risk mothers on non-routine health-care expenditures at 6 weeks postpartum (Brown & Johnson, 1998). The group receiving enhanced care by visiting nurses (n = 29) had an estimated cost of US$646, whereas the control group (n = 29) had a cost of US$6,631, which included clinic use, emergency room visits, hospital re-admission, and physician visits. The findings suggest that nurse home visits reduce utilization of some health services, but it is unclear which other factors affect costs associated with nursing and medical care.

Methods

Setting

At the time of the present survey (1999), Ontario had a population of 11.52 million and approximately 130,908 births annually (Statistics Canada, 2001). Five sites were selected from across the province (Table 1) to provide a cross-section of mothers and newborn infants with diverse characteristics and varied access to health and social services.

Table 1 *Site Characteristics*

Site	Characteristics	Number of Births Annually
Site 1	Large suburban teaching centre in central-eastern Ontario, metropolitan catchment area	3,900
Site 2	Small regional centre in central-eastern Ontario, urban and rural catchment area	1,500
Site 3	Large regional centre in central-western Ontario, urban and rural catchment area	4,500
Site 4	Large teaching hospital in central-eastern Ontario, metropolitan catchment area	2,700
Site 5	Small regional centre in central-northern Ontario, urban and rural catchment area	2,000

Study Design and Sample

The sample for this cross-sectional survey comprised the first 250 eligible, consenting mothers from each of the five sites, for a total of 1,250 subjects. Intake of subjects was started in November at the first site and thereafter staggered across sites. Data collection was completed by the following June. A woman was eligible if she had given birth vaginally to a single live infant, was being discharged from hospital at the same time as her infant, was assuming care of her infant at the time of discharge, and was competent to give consent to participate. Of the women screened, approximately 26% were ineligible. Of those who were eligible, 27% refused and 32% were missed due to time limitations on the part of the on-site research assistant at some sites. The study was conducted in seven languages (English, French, Spanish, Italian, Portuguese, Cantonese, and Farsi) to include women who were not fluent in English. The questionnaire was translated by a qualified translator and each subject was interviewed in her own language. This approach served to elicit important information about groups often thought to be at risk for poor health outcomes, which is lost in studies that include only English-speaking subjects.

Measures

The mothers completed a self-administered questionnaire prior to discharge and a structured telephone interview 4 weeks after discharge. The questionnaire addressed sociodemographics, use of prenatal services, medical problems since giving birth, chronic health problems, concerns at time of discharge, infant birth weight and gestation, infant feeding, infant health problems, and perceived adequacy of help and support available at home. It incorporated the Edinburgh Postnatal Depression Scale (EPDS) (Cox, Holden, & Sagovsky, 1987; Murray & Cox, 1990) as well as questions from both the Ontario Health Survey (Ministry of Health, 1992) and the Health and Social Service Utilization Questionnaire (HSUQ) (Browne, Gafni, Roberts, Goldsmith, & Jamieson, 1995). The telephone interview consisted of questions about length of hospital stay postpartum, information needs, maternal and infant health, social support, infant feeding, type and frequency of health and social services used post-discharge, re-hospitalization, and laboratory tests. Interviewers were health or social science students or professionals. They were given a script to follow and were individually trained by the research coordinator and the investigators in a standardized way that included practice and feedback sessions.

The health and social service utilization outcome variable was measured using an inventory developed by Browne, Arpin, Corey, Fitch, and Gafni (1990) modified for use with a postpartum population by the addition of service providers such as midwives, pediatricians, and obstetricians and questions about use of services for both mother and infant. The questions concerned the respondent's utilization of different categories of health and social services such as physicians, nurses, social workers, midwives, hospitals, and emergency rooms. Each mother was asked to indicate the number of visits and phone consultations separately for herself and her infant for each service used. Each category of visit was multiplied by the unit cost of the visit to yield a measure of cost for each health and social service as well as total cost for each mother, infant, and mother/infant dyad. Costs per visit were determined from appropriate sources such as the Ontario Health Insurance Plan fee schedule, clinic fees, hospital rates, and public health and other agency rates. Thus costs include a societal perspective as costs are accrued to the government and the person.

Analysis

Descriptive analysis was completed using means, standard deviations, and percentages. Correlations were carried out using continuous data where possible. Later continuous variables were dichotomized where clinically meaningful cutoffs were appropriate. For cost comparisons, the dichotomized variables were used. Stepwise regression analysis was performed to determine associations with the continuous variable, costs.

Results

Response Rates

Of the 1,250 participants, 875 (70%) completed the follow-up interview (3% refused, 20% could not be located, 4% were located too late, and 3% did not complete it for other reasons), although only 873 (99.8%) of these completed the HSUQ section for themselves and their infant. Fifty-seven mothers did not report their income category. There was no difference in age, parity, or length of stay for the subjects and those who refused or were missed.

Description of Participants

At baseline, 92% of the women indicated that they had a partner and 78% were married, 18% reported an income of less than $20,000 per

annum, 16% spoke neither English nor French as their first language, and 75% had at least a high school education. The mean age of the women was 30 years. The infant mean birth weight was 3,503 ± 468 grams, mean gestation was 39.5 ± 1.4 weeks, and for 43% of the mothers it was their first live birth. At discharge, 89% of the mothers were breastfeeding and 15% indicated that they had little or no support or help at home. Eighty-five percent of mothers had a postpartum hospital stay of 48 hours or less. Only 1.6% of the infants had low birth weight (less than 2,500 grams) (Sword et al., in press).

At 4 weeks post-discharge, 15% of mothers had many learning needs related to their infant's and their own health and care (such as infant feeding and signs of illness and their own health and emotional changes); 16% had some/slight concerns about their infant's health, and 3.3% indicated that their own health was poor. The rate of clinical depression (defined as ≥ 12 on the EPDS) was 10%; 11 women (1.3%) indicated higher depression scores (> 19 on the EPDS).

Costs of Health and Social Care

The average costs of care for mother and infant in the first 4 weeks post-discharge were measured for all health and social services (Table 2). The greatest costs were for physician care and re-admission of infant to hospital.

The five sites showed a range in the mother and infant mean cost of health and social services excluding re-admissions ($207–$355) and including re-admissions ($327–$665) (Table 3). The variation may be related to use of pediatricians and reason for infant re-admission (e.g., one site routinely re-admitted for jaundice). However, differences among sites were not statistically significant. A total of 1% of mothers and 4% of infants were re-hospitalized. In summary, the eight maternal re-admissions were for infection (3), bleeding (2), congestive heart failure (1), D&C (1), and gallbladder (1). The 36 infant re-admissions were for infection (14), jaundice (12), constipation (2), vomiting (1), distended abdomen (1), and other (6). Although re-admission costs for some mothers and infants were extensive (up to $19,032), the mean costs for the sample ranged between $0 and $72 on average per mother/infant dyad at the different sites. Further, there was wide variability (high standard deviations) in the total cost of utilization per mother/infant dyad when re-admission costs were included, because few mothers and infants were re-admitted and, for those who were re-admitted, the length of hospital stay varied.

Table 2 *Costs of Care for Mother and Infant*

Descriptive Statistics	Range ($)	Mean ($)	Std. Dev. ($)
Mother (n = 875)			
Family physician	0–337.5	19.14	34.42
Family physician house call	0–77.6	0.40	5.07
Specialist	0–108.8	0.99	8.96
Midwife	0–219	11.26	48.40
Obstetrician/gynecologist	0–111	3.21	11.70
Emergency room	0–258.37	6.20	28.98
Walk-in clinic	0–78	0.95	6.02
Physiotherapist	0–488.88	0.98	18.23
Occupational therapist	0–83.94	0.19	4.01
Social worker	0–530.25	2.67	23.64
Nutritionist	0–505.85	2.43	25.72
Public health nurse visit	0–814.45	14.84	47.70
Public health nurse phone consultation	0–459.25	6.13	23.15
Other visiting nurse visit	0–498.74	16.89	39.54
Other visiting nurse phone consultation	0–91.85	3.65	12.26
Homemaker	0–564.6	0.90	20.55
Chiropractor	0–415.8	3.99	25.23
Psychologist	0–251.1	0.57	12.00
Psychiatrist	0–123.86	0.28	5.12
Other health-care provider	0–315	3.77	21.30
Medical supplies/aids/devices	0–350	9.00	32.47
Laboratory testing	0–100.55	2.23	9.32
Total utilization excluding hospital stay	0–1,760.56	110.70	144.00
Hospital stay	0–11,102	31.72	459.62
Total utilization including hospital stay	0–11,302.1	142.42	493.49

Descriptive Statistics	Range ($)	Mean ($)	Std. Dev. ($)
Infant (n = 873)			
Family physician	0–337.5	69.80	45.14
Family physician house call	0–38.8	0.09	1.86
Midwife	0–219	11.79	49.46
Pediatrician	0–230.4	10.15	21.27
Specialist	0–108.8	1.00	8.97
Emergency room visit	0–775.1	13.17	54.28
Walk-in clinic	0–78	2.29	8.99
Physiotherapist	0–0	0.00	0.00
Occupational therapist	0–0	0.00	0.00
Social worker	0–212.1	0.85	10.74
Nutritionist	0–404.68	1.74	21.87
Public health nurse visit	0–428.65	13.31	36.69
Public health nurse phone consultation	0–183.7	4.95	15.71
Other nurse visit	0–498.74	23.11	48.31
Other nurse phone consultation	0–91.85	3.45	11.42
Homemaker	0–0	0.00	0.00
Other health professional visit	0–266	2.99	18.54
Medical supplies/aids/devices	0–300	3.27	20.14
Outpatient diagnostic testing	0–314.81	6.96	25.15
Total utilization excluding hospital stay	0–1,203.37	170.02	125.17
Hospital stay	0–19,032	142.61	1,042.41
Total health utilization	0–19,689	312.63	1,088.15
Both Mother and Infant			
Total utilization excluding hospital stay	0–2,362.8	280.79	228.43
Total utilization including hospital stay	0–2,0119.5	455.20	1,216.00

Table 3 *Total Health and Social Service Costs for Mother and Infant*

	Site 1		Site 2		Site 3		Site 4		Site 5		
	n = 164		*n* = 200		*n* = 209		*n* = 137		*n* = 165		Total
	Mean	*SD*	*Mean*	*SD*	*Mean*	*SD*	*Mean*	*SD*	*Mean*	*SD*	*Mean* *SD*
Health/social services* excluding hospital re-admission	$298	(206)	$207	(232)	$285	(213)	$355	(244)	$286	(228)	$281 (228)
Health/social services* including hospital re-admission	$665	(2,171)	$362	(866)	$327	(533)	$517	(882)	$469	(1,091)	$455 (1,216)

*p = NS

Factors Associated with Costs of Care

Fourteen sociodemographic and clinical variables were selected a priori as potential correlates of health and social service costs: (1) language spoken at home (English or French vs. other); (2) family income (< $20,000 vs. $20,000+); (3) partnered or unpartnered; (4) age (< 22, 22–34, or > 34 years); (5) education (high school or less vs. > high school); (6) first live birth versus second or subsequent birth; (7) length of hospital stay; (8) number of maternal learning needs; (9) perceived adequacy of help at home; (10) postpartum depression; (11) self-reported health status; (12) infant birth weight (< 2,500 vs. 2,500+ grams); (13) feeding method (breast vs. bottle); and (14) infant health status as reported by mother.

Eight variables correlated with total health and social service utilization costs for mother and infant during the 4 weeks. Overall costs were lower if: (1) the mother spoke English or French ($r = .067$; $p = .049$); (2) the mother had a partner ($r = .157$; $p < .01$); (3) family income was $20.000+ ($r = -.113$; $p = < .01$); (4) the mother's health was not poor ($r = -.113$; $p < .01$); (5) the infant's health was good to excellent ($r = -.396$; $p < .01$); (6) the mother had adequate help and support at home ($r = -.266$; $p < .01$); (7) the mother had lower depression scores ($r = .174$; $p < .01$); and (8) the mother had fewer learning needs ($r = .120$; $p < .01$).

Nursing and Medical Costs

The total cost for community-based nursing care, including visits and phone consultations by public health nurses, clinic nurses, and community visiting nurses, averaged $86 per mother/infant dyad. The total cost for medical care, including visits and phone consultations with family physicians, midwives, obstetricians, pediatricians, psychiatrists, and other specialists, averaged $129 per dyad. Because the data were collected at 4 weeks post-discharge, in most cases utilization did not include the physician follow-up visit regularly scheduled for women at 6 weeks.

Although 43% of mothers and infants did not receive any nursing care during the 4 weeks, only 1.3% did not receive any medical or midwifery care. Nursing costs ranged from $0 to $1,096 per dyad, and medical and midwifery costs ranged from $0 to $717.

Stepwise multiple regression analysis found five factors to be significantly associated with higher nursing costs ($F = 20.58$; $p < .001$). In order of significance, these were: more than five self-identified learning needs, mother's perception of her own health as poor, mother's percep-

tion of inadequate help and support at home, high maternal depression scores, and postpartum hospital stay of 48 hours or less. In total, the variability of these factors accounted for 11% of the variability in costs for nurse contacts. Costs were as follows: $144 for women with more than five learning needs, versus $70 for those with fewer needs; $189 for women who rated their own health as poor, versus $83 for those who rated their health as very good to excellent; $250 for nurse contacts for women with high depression scores (> 19 on EPDS), versus $84 for those with low scores; $128 for women indicating inadequate help and support at home, versus $79 for those indicating adequate help and support; and $90 for community nursing care for women who stayed in hospital 48 hours or less, versus $66 for those who stayed longer.

Stepwise multiple regression analysis found poverty to be the only characteristic of mothers or infants significantly associated with higher medical costs ($F = 2.82$; $p = .005$). Medical (physician and midwife) costs were $152 for mothers with a low family income (< $20,000 annually), versus $124 for those with a higher income. This variability in income level accounted for 1% of the variability in medical costs. Although this may seem insignificant — at $28 more per child in a poor family over the 4 weeks — it is not insignificant if the trend towards greater utilization and higher costs continues.

Costs Related to Mothers with Depression

Costs were notably different for mothers with and without depression as determined by an EPDS score of ≥ 12 (Table 4). The total cost for health and social care was $845 for mothers with depression and their infants, versus $413 for those with lower scores ($p < .01$). The total cost was $2,137 for 11 mothers with high depression scores (> 19 EPDS), versus $434 for those with lower scores. Most of the $2,137 was accounted for by care for the infant, including hospital re-admission ($1,767), rather than for the mother ($370).

For women with higher depression scores (≥12 EPDS), combined medical costs were not significantly higher statistically ($133 vs. $128); however, pediatrician costs were higher and community nursing costs much higher ($135 vs. $81) per mother/infant dyad on average ($p < .01$). For women with EPDS scores of > 19, community nursing care was three times higher ($250 vs. $84) per dyad. For mothers with depression ($p < .01$), social work costs were greater ($11 vs. $2). Of the women with an EPDS score ≥12, only one was seeing a psychologist and one a psychiatrist; the latter was receiving psychotropic medication for a previously diagnosed bipolar disorder.

Table 4 *Average Costs of Care for Mothers and Infants in First 4 Weeks Postpartum*

	Total ($)	Mothers with Depression (n = 86) ($)	Mothers without Depression (n = 787) ($)	Mann Whitney (p)
Nurse	86.3	134.5	80.8	.006*
Medical	128.2	132.8	127.6	.86
Pediatrician	10.1	16.1	9.5	.001*
Social work (mother)	3.5	11.1	1.8	.006*
Hospital (mother)	31.7	36.9	31.2	.86
Hospital (infant)	142.5	451.8	108.9	.73
All costs	455.0	845.0	413.0	.02*

*Statistically significant

Conclusions

Infant re-admission to hospital constituted the greatest proportion of health-care costs in the 4 weeks following postpartum discharge, even though only 4% of infants were re-admitted. However, given the fact that infant health problems could have been identified and treated prior to early discharge, the total number of hospital days, and hence costs, for infants with identified problems may not have increased (Sword et al., 2000). The fact that physician and midwife care accounted for a high proportion of costs is not surprising and may reflect, in part, adherence to guidelines for infant follow-up. The CPS and SOGC recommend that all infants be seen by a qualified health-care provider within 7 days of birth, and that infants discharged within 48 hours of birth be seen within 48 hours of discharge (Fetus and Newborn Committee, 1996). Further research is needed to explain the inverse relationship between income and physician/midwife use.

The relationships between nursing costs and learning needs, self-reported health status, perception of help and support at home, EPDS score, and length of hospital stay suggest that mothers with specific postpartum needs are making appropriate use of the nursing services available to them in their communities. These relationships might be made clearer if future studies address the reasons for nursing visits as well as the reasons for the higher overall service utilization and costs

for women with family incomes under $20,000 and women with clinical depression. The association between depression and service use, although not necessarily casual, is particularly interesting. The greatest cost differential was that for care provided by community nurses and social workers ($p < .01$). However, of the women who scored 12+ on the EPDS, only 22.2 to 30.8% reported that they had experienced an emotional or mental health problem since discharge, none reported seeing a mental health specialist or taking antidepressant medications, and none increased their use of medical care, which suggests that this health problem went unrecognized by the medical profession (Watt, Sword, Krueger, & Sheehan, submitted). The increase in nursing and social work costs but not in medical costs might reflect the fact that medical visits are regularly scheduled for newborn infants whereas visits by nurses and social workers are based on client need. It appears, from the results of this study, that nurses and social workers have an important role to play in case finding, referral, and provision of services for mothers with postpartum depression.

Although these findings have implications for policy-makers and health practitioners, there are limitations to the study. Because they are based on a consecutive sample of consenting women who had given birth to a live, singleton infant being discharged with the mother, the findings cannot be generalized to a wider population. In addition, the inter-site variability suggests that postpartum needs of mothers and infants vary across communities in Ontario. An additional limitation may be the measurement of service utilization; mothers had to recall every health and social service used in the previous 4 weeks.

The literature rarely addresses the postpartum utilization of health and social services. The findings of the present study are consistent with the finding reported for the United States and the United Kingdom that length of stay appears unrelated to total increased health-care costs in the early postpartum period. Although the present study found length of stay to be related to greater use of nurse visits, this utilization seems to be offset by less utilization of a combination of other health-care services. In addition, Hakansson et al.'s (1996) finding of a relationship between lower income and health-care costs over an 18-month period supports the present finding of a relationship between poverty and increased health-care costs in the first 4 weeks postpartum.

This study was completed prior to implementation of the Hospital Stay and Postpartum Home Visiting component of the Healthy Babies, Healthy Children Program in Ontario. The goal of this program is to provide all women the option of a 60-hour postpartum stay, a phone

consultation with a public health nurse within 48 hours of discharge, and a home visit by a public health nurse. Although this initiative has the potential to address needs and enhance linkages to various community-based services, it is unclear what the effect might be on overall health and social service utilization.

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Towards Ethical Inquiry in the Economic Evaluation of Nursing Practice

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L'évaluation de la pratique infirmière selon des critères économiques constitue un outil essentiel dans le domaine des soins infirmiers et des soins de santé. Les auteurs affirment que la cueillette de données économiques doit être faite en tenant compte des données éthiques, et que la profession infirmière se doit d'examiner les valeurs en même temps que l'aspect économique. En s'appuyant sur deux études ethnographiques portant sur la pratique infirmière, les auteurs mettent en lumière le travail invisible des infirmières, la tâche invisible que constitue le triage de clients ainsi que les coûts invisibles que doivent payer les infirmières et les clients. Selon eux, le travail, la tâche de triage et les coûts invisibles relèvent profondément de certaines valeurs, et si la profession infirmière est tenue de réagir aux conséquences de la réforme de santé, celle-ci doit se pencher sur les valeurs inhérentes au mesurage économique et sur les décisions qui en découlent sur le plan des politiques de santé. Ce qui est invisible peut échapper à la « comptabilisation », à moins que l'évaluation économique ne soit fondée sur une cueillette de données éthiques. En conclusion, les auteurs suggèrent d'intégrer la cueillette de données économiques et éthiques dans le but de favoriser la mise en place d'un système plus humain, qui dessert, de façon plus efficace, tous les intervenants œuvrant dans le domaine de la santé.

Economic evaluation is a critical tool for nursing and health care. The authors claim that economic inquiry needs to be supported by expertise in ethical inquiry, that the nursing profession needs to examine values concurrently with economics. Drawing on 2 ethnographic studies of nursing practice, the authors illustrate nurses' invisible work, their invisible triaging of clients, and the invisible costs to nurses and clients. They argue that invisible work, triage, and costs are embedded in a number of values, and that if nursing is to respond to the consequences of health reform, it must examine the values inherent in economic measurement and subsequent health-policy decisions; what is invisible may go "uncounted" unless economic evaluation is informed by ethical inquiry. The authors conclude by suggesting that economic and ethical inquiry be integrated in order to foster a system that is more humane as well as more effective and efficient for all those involved in health-care delivery.

Nurses in all arenas of practice across Canada, as well as in other Western industrialized countries, are facing excessive workloads, a shortage of skilled colleagues, a decimated cadre of nurse leaders, and increasing acuity/distress among patients/clients, families, and com-

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munities (Acorn, Baxter, & Walker, 1999; Adams & Bond, 2000; Aiken, Clarke, & Sloane, 2000; Canadian Nurses Association, 1998; Nagle, 1999; Redman & Fry, 2000; Rodney & Starzomski, 1993; Sochalski et al., 1998; Varcoe & Rodney, in press; Woodward et al., 1998). At the same time, nurses are being challenged to examine — indeed, defend — the economic aspects of nursing practice. This issue of the Journal is testament to the importance of nursing expertise in measuring the cost implications of nursing services. In this paper, we will argue that economic inquiry needs to be supported by expertise in ethical inquiry; that is, we believe that our profession needs to examine *values* concurrently with economics. A new but growing body of research is warning that the past decade of health-care reform has been one of profound deterioration in the conditions of nurses' work, with increasingly deleterious effects on health-care delivery (Adams & Bond; Aiken et al.; Barry-Walker, 2000; Mohr, 1997; Mohr & Mahon, 1996; Redman & Fry; Reinhardt, 1997; Reynolds, Scott, & Austin, 2000; Shindul-Rothschild, Berry, & Long-Middleton, 1996; Sochalski et al.; Varcoe & Rodney; Woodward et al.). If we are to respond to and reverse the consequences of health reform, it is crucial that we examine the values that are inherent in economic measurement and subsequent health-policy decisions.

In order to support our methodological reflections, we will draw on results from our own qualitative studies describing nursing practice and the cultural context of health-care delivery, as well as other relevant empirical data. Rodney's (1997) feminist ethnographic account of nurses' enactment of their moral agency included over 200 hours of participant observation on two acute-care medical units, with 22 interviews with 11 nurses from acute care and three from home care. Varcoe's (1997) critical ethnographic account of nurses' practice in relation to violence against women was conducted in the emergency units of two hospitals and their communities. The latter study involved over 200 hours of participant observation and interviews with 45 participants, including nurses, social workers, physicians, clerks, and patients (see also Varcoe, 2001; Varcoe & Rodney, in press).

In this paper, we intend to shed light on some of the values inherent in health care that, if not critically examined, may distort the economic evaluation of costs. We will explicate the often invisible, and frequently paradoxical, processes involved in day-to-day rationing of nursing and other resources. We will conclude by suggesting how we might integrate economic and ethical inquiry to foster a system that is more humane as well as more effective and efficient for all those involved in health-care delivery — patients/clients, families, communities, providers, and practice leaders.

Unseen Nursing

> As the health system changes and continues to become more complex, there is increasing emphasis on the need for greater co-ordination and integration. There is a challenge to find new ways of conceptualizing health, and new ways of organizing, delivering, financing, and evaluating health services. (Giovannetti, Smith, & Broad, 1999, p. 298)

Despite the mandate to evaluate services, *nursing* services remain largely invisible to other providers, to administrators and policy-makers, and to theorists in fields such as bioethics and health economics (Campbell, 1987, 1994; David, 2000; Giovannetti et al.; Liaschenko, 1993a, 1993b; Stelling, 1994a, 1994b; Street, 1992; Varcoe & Rodney, in press). As Giovannetti et al. explain, "data that reflects the demand for nursing care, the response of nurses to that demand, and the contribution of nurses to the public's health, is generally not available for use in planning, managing, and evaluating the effectiveness of the health system" (p. 306). Clearly, this is of concern. What remains invisible is all too easy to dismiss, and what *does* get measured does not necessarily reflect the full worth of nursing services (Giovannetti, 1994; Mitchell, 1993).

Meanwhile, federal, provincial, and regional health-policy changes in Canada, while occurring at an unprecedented rate and while unparalleled in scope (Brown, 1996; Storch & Meilicke, 1994, 1999), are largely uninformed by a comprehensive analysis of nursing and nursing practice. This has potentially disastrous consequences for nursing practice and health-care delivery (Armstrong & Armstrong, 1996; Canadian Nurses Association, 1998). To illustrate, let us turn to the province of Alberta. Brown (1996) writes that in 1993 Alberta "initiated a set of financial reforms for its health care sector, modeled in general terms after reforms already implemented in New Zealand and Britain" (p. 137). The key feature of the reforms was the creation of 17 Regional Health Authorities (RHAs), thus replacing the single provincial budget authority with 17 budget authorities and charging them with responsibility for funding health-care activities. This reform effectively created a split between the demanders (RHAs) and suppliers (health-care providers) by expecting potential suppliers to bid for business. Brown explains that these moves were based on the ideology of economic rationalism, in which public-sector intervention to create managed markets is seen to be feasible and efficient where competitive markets do not naturally evolve. Among the effects of these changes were a distancing of health-care providers from health policy-makers, an emphasis on health-care processes rather than on health outcomes, and equity being given short shrift relative to efficiency (Brown, p. 139).

Such changes might be expected to distance nurses from health policy and support nursing "efficiency" over care aimed at health outcomes or equity.[1] Indeed, in 1994 the Alberta Association of Registered Nurses released the results of a survey it had undertaken to assess the impact of the reforms on patients/clients, families, and communities (Oberle & Grant, 1994). Responses from nurses across the province concerning staff cutbacks were frightening. For instance, elderly residents were reported as being inadequately fed in nursing homes and seriously ill children were reported as being discharged prematurely from emergency departments (Oberle & Grant). It is our experience, and the experience of nursing colleagues across the country from whom we have heard, that the situation in Alberta was not unique.

However, much of the impact of health-care "reform" on nursing is invisible and therefore overlooked. In fact, there is a startling lack of evaluative data on the impact of health-care reform measures in Canada, the United States, and elsewhere on outcomes for clients[2] as well as providers (Aiken et al., 2000; Sochalski et al., 1998). Below, we draw on our own research to shed light on aspects of nurses' work that are likely to be invisible and/or underestimated in economic evaluations of nursing care. Our data were collected between 1995 and 1997 in a Canadian province that was undergoing regionalization and rationalization of health-care delivery. We argue that under the economically driven changes that characterize recent health-care reforms, only certain processes are costed. Thus only certain aspects of care are accounted for and funded, while significant aspects of nursing care are not. Our research has led us to be particularly concerned about nurses' invisible work, the invisible triaging of clients, and the invisible costs to nurses and clients. We will suggest that different values underlie what gets accounted for and what is overlooked in economic evaluation and subsequent health-policy decisions.

Invisible Work

An important aspect of invisible nursing work identified from our studies was *nurses' emotional labour* — that is, fulfilling patients' needs

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[1]Equity is not the same as equality. The word equality, though often misused or misinerpreted, means the state of *being* equal. Equity, on the other hand, means fairness or equality of *treatment*. Thus inequity (or unequal treatment) can result in unfair allocation decisions.

[2]Hereinafter, when we use the term "client" we are referring to all those who are the target of nursing practice — patients/clients, families, and communities.

for emotional support (Yyelland, 1994; see also Varcoe & Rodney, in press). According to the nurses in our two studies, one of the greatest impacts of limited resources was that the nurses did not have time to "talk" to patients. Everything within the context of practice — from the allocation of the workload, to the geography of units (maximum surveillance, minimum privacy), to the design of charts — fostered the devaluing of non-physical concerns. Nurses' emotional labour was therefore found to be particularly undervalued in both studies. Under the increasing pressure of high acuity combined with cost-saving measures, such work was the lowest priority. Most nurses at all study sites worried about their inability to attend to these patient needs. One nurse said:

> *Sometimes due to the busyness of the department you don't really have a chance to get into the emotional aspect of it…you don't really have the time…to sit down and say "really, what really happened?"* (Varcoe, 1997, p. 251)

Even when patient needs for emotional support were particularly high, as in the case of a death, terminal diagnosis, or severe trauma, nurses were unable to make such work a priority. Many nurses told of such situations. Their inability to provide support caused them distress that lingered long after the incident. For example:

> *I get really angry when I don't have the time to spend with the patients and yet…there are lots of times that I'm thinking "thank God they don't want it." I remember asking somebody, he had just been diagnosed with lung cancer, and saying "do you want to talk about it" and he said "no, I'm not quite ready to talk about it" and honest to God I just said [to myself] "thank God" because I had a gazillion other things to do.* (Varcoe, 1997, p. 128)

Emotional labour was not only devalued but actively discouraged. Nurses spoke not only about lacking the time for what they referred to as "the psychosocial," but also about how colleagues who *took* the time to talk to patients were criticized because they interrupted the work flow. Many nurses expressed derision for "bleeding hearts" or for those who were "slow," spent "too much time talking," and so on. As one nurse explained:

> *[We] don't support each other…one of the nursing staff…has a very strong psych background and she wants to do that, and so her colleagues get frustrated because she's behind in this, that and the other thing. And I said "Well, what was she doing to get behind?" "She's talking to patients!"* [laughs] *All right, I forgot we don't do that here* [laughs] *you know, and I mean it's a dilemma because…you've got to get your ten*

> *o'clock meds out sometime around ten o'clock, you know, at least before the two o'clock ones are due.* (Rodney, 1997, pp. 145–146)

A second important — and related — invisible aspect of nurses' work was their *systems work*. This involved dealing with issues that have no "place" in the organization, such as social problems beyond the official mandate of the hospital, in ways that were unlikely to be noticed. In the emergency setting, for instance, nurses were required on a daily basis to deal with people who were brought to the hospital because no one knew what else to do with them. One nurse described this kind of situation:

> *People don't have the support of their families or the church or whatever and a lot of the time they end up in Emergency because nobody knows what else to do with them. The police bring them in because they don't know what to do with them, or the ambulance goes to the situation and they don't really think this is a physical problem but they bring them in because they don't know what else to do with them and therefore, it is becoming more and more frequent that we are the catchment area for people who are slipping through the hole some way or other.* (Varcoe, 1997, p. 121)

People with mental illness, drug or alcohol problems, or social problems secondary to poverty were seen by nurses as ending up in hospital whether or not they had an immediate health issue requiring hospital services. Moreover, systems work included nurses' support of vulnerable families coping with the discharge home of fragile (often elderly) patients. An experienced nurse recounted a situation on a medical unit:

> *This little lady who had bad rheumatoid arthritis…she was requiring two people to get her up and to get her into the commode and she didn't want to sit up and she was…having major trouble…yet she was going to go…home, which is with her daughter and son-in-law. The daughter is taking chemo and is really quite sick with her chemo, and there's a son-in-law who's in his sixties trying to…look after the two of them and I think he probably had an awful lot on his plate. [The patient was] just a sweetheart but she required a lot of care so I said to her doctor, "Well, what are the plans for this lady?"…you've got to find out these things.* (Rodney, 1997, p. 177)

Without the nurse's actions in notifying the physician and initiating assessment and follow-up, the consequences for this client and her family might have been serious. Yet the nurse's actions would not have shown up readily on a workload measurement index, and may have been overlooked — along with the client's problems — by her nursing and medical colleagues.

Invisible Triage

Our research also provides evidence of economic allocation decisions at a micro level — or triage decisions — that are obscured by established costing mechanisms in health care and are thus not likely to be taken into account in economic evaluation. Two complex and interrelated processes that we observed were *emotional distancing* from patients in order to preserve work time for other priorities and *rationing of care based on judgements about deservedness* (see also Varcoe & Rodney, in press).

Nurses routinely distanced themselves emotionally from patients in order to preserve time for the nursing work that "counts." Since emotional labour is often invisible, many nurses used this strategy. In the study with emergency nurses, for example, nurses complied with the demands of the organization by becoming more "efficient"[3] and emotionally "strong," which meant focusing on physical care and not engaging with patients. Nurses felt they could not afford to engage with patients, partly because of time constraints and partly because of the need to be ready for the unknown. Repeatedly, nurses described the ways in which time constraints affected their interactions with patients:

> *When you are looking at your seven patients and you've got IV antibiotics to start here, you've NG's [nasogastric tubes] to put down there...and you've got this to do, that, and the next thing you know you get a new patient and there is just too much to do. So you are running around as fast as you can go, doing as much as you can but you are not talking to the patient. As a matter of fact you are almost a little bit relieved if the patient isn't talking because then you don't have to slow down.* (Varcoe, 1997, p. 180)

One nurse explained that nurses developed ways of curtailing conversations with patients to keep them "on track" — in line with the needs of the organization. In addition to making the nurse more "efficient," this emotional distancing helped her to cope with the distress of witnessing human misery and being unable to deal with it effectively:

> *Open ended questions...that we don't have to do now because we can manipulate answers out of patients. One word answers like you've never seen. But feelings, senses, that's another story, 'cause that involves time and it involves an investment on your part...and I think that as an Emergency nurse I have learned...I am protective now of myself. I am not prepared to give as much as I used to, and I'm certainly not proud of it,*

[3]The terms "efficient" and "efficiency" are used as intended by the nurses in the study — to mean the rapid processing of patients under particular economic conditions.

> *but it is safer…I'm not prepared to be bitten, for a little while. I may never be prepared.* (Varcoe, 1997, p. 151)

Under the conditions of practice in the units studied, there was simply not enough of each nurse to meet the requirements of care. Despite emotionally distancing themselves and remaining as efficient as possible, nurses often could not keep up with the tasks dictated by policy and minimum safety requirements. For example, nurses were often caring for so many patients in such spatially separate areas that they were unable to properly monitor patients or provide adequate pain management (Rodney, 1997; Varcoe, 1997). Because nurses lacked the time to provide the care they saw as necessary, their standards of care were affected:

> *Even for those nurses who really do value them [the elderly] and want to do good…they go into the work situation with escalating work loads to the point where…one of the nurse managers on another medical unit said to me the other day, "You know" she said, "We're just back into restraints again" …I haven't seen [restraints] for so long, we've been working so hard at it [getting rid of restraints], but it's like all of that goes out the window…when the pressure of work load is in place and I should think that goes back into the guilt [nurses feel] because the more knowledge you have the more guilty you're going to feel.* (Rodney, 1997, pp. 234–235)

In such situations, nurses must decide "what care can be hurried over, skimped on, or deleted completely" (Campbell, 1994, p. 602). Thus decisions had to be made about which patients would receive less care. Most decisions on the rationing of care were based on physiological acuity, but a disturbing number were based on covert social criteria regarding "who deserves what care."

In both studies, the patients routinely seen as less deserving were those who had substance-use problems, were demanding or abusive, used health-care services frequently, or were perceived to be using health-care services inappropriately and making little effort to take responsibility for their health and their lives. These judgements apparently arose partly from the way in which some patients treat nurses and other health-care providers. Nurses are regularly verbally abused and often physically assaulted (Armstrong & Armstrong, 1996; Croker & Cummings, 1995; Mahoney, 1991; Schnieden & Marren-Bell, 1995). In addition, nurses in both studies often spoke of those who over-use the system as contributing unreasonably to their workload. One nurse said:

> *I've lost it. There are some repeaters that we have, frequent flyers we call them, that on a good day, if you haven't been busy you can deal with them, but on other days you need to say "listen I can't deal with this*

> *particular patient right now, it is not to the patient's advantage."* (Varcoe, 1997, p. 177)

However, underlying these and other judgements regarding deservedness were the ideas, images, and assumptions of nurses and other health-care providers, particularly about class. For example, it was not merely alcohol abuse that made a person less deserving; it was being poor and abusing alcohol — for poverty made individuals more open to the scrutiny of health-care providers and poverty made alcoholism more visible. "Frequent flyers," the people who use emergency and other acute-care services repeatedly, generally have multiple health and social issues, most commonly poverty, chronic illness, mental illness, and drug or alcohol abuse. For some nurses, such judgements about deservedness by their colleagues were a significant source of moral distress. One participant said:

> *My discomfort comes when I am given this kind of patient [a patient with a history of intravenous drug use and who is in severe pain] and I am given [an order for] Tylenol Three, you know...and then I have to ask [for a stronger analgesic] and then I have to sort of explain and it's almost like explaining away to a wall, and it's very difficult for me because the others are thinking, "What is she doing?"* (Rodney, 1997, p. 162)

The insight that nurses make social judgements about patients is beginning to emerge in the literature. Studies have been done of nurses' construction of patients as good or bad, popular or unpopular — and the role of social judgement in power relations, clinical decision-making, and pressure to get patients to acquiesce to nursing and medical goals (Carveth, 1995; Corley & Goren, 1998; Greif & Elliot, 1994; Johnson & Webb, 1995a, 1995b; Kelly & May, 1982; Liaschenko, 1995; McCormick, 1997). We suggest that in the current climate of fiscal constraint, however, nurses are more predisposed to allocate their services based on covert and ethically questionable judgements about deservedness[4] (see also Corley & Goren; Stevens, 1998).

Invisible Costs

What are the consequences of invisible work and invisible triage? Let us start by discussing the costs for *nurses*. In both of our studies,

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[4]We would like to make it clear that we do not see nurses' allocation of their services based on covert and ethically questionable judgements about deservedness as a *new* phenomenon. Nor are nurses the only providers who engage in this kind of covert triage. Our concern is that it has *worsened* in the current era of fiscal constraint. We see nurses as having to operate within a pervasive and disempowering *ideology of scarcity* (Varcoe, 1997, 2001; Varcoe & Rodney, in press).

nurses all too often had to either donate their own time to fulfil even minimal care requirements, or provide less care and suffer moral distress,[5] or provide less care and consider it adequate (see also Varcoe & Rodney, in press). Because there was insufficient time to do the work that was "expected" (as evidenced by charting requirements, policies, and practice norms), and because they saw both emotional labour and systems work as important, nurses routinely worked through their allotted breaks and beyond their assigned work hours. Donations of time were a constant feature of nurses' work in the units we studied. At one emergency site (Varcoe, 1997) and in one medical unit (Rodney, 1997) nurses were routinely observed staying from 15 to 30 minutes after their 8- or 12-hour shift was over, to complete their charting, deal with an unexpected crisis with a patient, assist with an admission, or provide basic care for a patient that had not been provided during the shift. When asked about this, the nurses said they needed the extra time to finish their work and did not like to leave things undone. Interestingly, they did not claim overtime for the extra work unless they felt it was an unusual situation. They apparently made these donations for their own peace of mind. Many described going home distressed over unfinished work. In fact, some nurses associated losing the willingness to donate time with becoming "burned out." One nurse said that as part of her burnout she had become complacent:

> *She said "I used to go home and think 'I didn't do this, I didn't do that,' but now I just..." She shrugs. She says that she doesn't worry about obvious things, like did she take that patient off the bedpan but less obvious things that might be missed.* (Varcoe, 1997, p. 123)

In all of the units, the nurses appeared to be continuously engaged in a race against the clock to complete their required tasks. Any extra or unexpected events (such as the admission of a new patient or the dying and death of a patient) strained their workload to the point that they frequently shortened or skipped a meal break or stayed overtime. On one unit, the workload measurement system indicated that nurses were routinely working at 110% of their capacity. One of the practice leaders

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[5]Moral distress is what nurses experience when they are unable to act fully on their moral intentions. It appears that when nurses are constrained from moving from moral choice to moral action, they experience anger, frustration, guilt, and powerlessness (Erlen & Frost, 1991; Fenton, 1988; Gaul, 1995; Holly, 1993; Jameton, 1984; Redman & Fry, 2000; Rodney, 1988, 1994, 1997; Rodney & Starzomski, 1993; Rushton, 1992; Varcoe & Rodney, in press; Wilkinson, 1985, 1987/88, 1989). It is worth noting that nursing and other disciplines need more empirical and theoretical work on the concept.

commented on the nurses' ability to provide good care under these conditions:

> *So the number of defined needs on any given day and the number of staff available to meet them [are barely adequate], and you usually feel that ten percent on either side is manageable, obviously…if you're functioning at a hundred and ten percent, you're still not meeting all patient needs and you're working fairly flat out…the majority of nurses…want to do good, it's hard to do good when you're working [at 110%].* (Rodney, 1997, p. 222)

Among the nurses we observed, the impact of being unable to fulfil their work obligations was substantial. It included guilt, fatigue, and taking sick time and stress leave. Guilt was identified, for example, by the practice leader we cited earlier: "The more knowledge you have the more guilty you're going to feel" (Rodney, 1997, p. 235).

A significant level of personal fatigue was associated with the "busyness" of nursing work. Nurses in both studies spoke of being exhausted at the end of most shifts. In the medical units the physical demands of providing basic nursing care to elderly and dependent patients were substantial and there was an almost desperate struggle to complete the required tasks before the end of the shift (Rodney, 1997). In the emergency units there was a chronic sense of urgency, of the need to be ever-alert and prepared for the next multiple trauma or disaster (Varcoe, 1997). The sense of fatigue was particularly apparent for those nurses who had dependent children at home. One nurse who needed to go straight home after work to look after her young child described how conflicted she felt if she had to stay late to provide extra care (Rodney, 1997). And nurses agreed that their level of busyness had increased over the preceding few years, making it increasingly difficult for them to balance the demands of work and home life. So while nurses face the same kind of home responsibilities they have for years (even if their partners are available and engaged in child care), they face increasing demands in workplaces such as those we observed.

Not surprisingly, nurses' psychological, social, and physical health was affected by the cumulative effects of being overworked and unable to provide the kind of care they wanted to give (see also Varcoe & Rodney, in press). Nurses who stayed on the job often coped by using sick leave or stress leave. Others left the department in search of better working conditions, or left nursing altogether. For instance, in one of the emergency units studied, five of the 12 nurses initially interviewed described themselves as burned out — and within a year of the study all five had left. One of them said:

> *I think I'm tired. I think I am really frustrated by not being able to do something on a major scale. I see a lot of my mates that I work with frustrated in our area. In our department, a lot of people have left out of pure frustration. I thought I never would be, but I am now. It's money, it's management, it's things I can't really argue with...maybe we are not doing a good enough job... But if there is one thing that I hear in our department [it] is that our nurses really care and they really give 100%. But I think they are tired. Emergency is a challenging area.... It is so mentally draining. I feel sad.* (Varcoe, 1997, p. 169)

In summary, organizational priorities and processes implied a valuing of aspects of nursing work different from the aspects valued by nurses. Faced with excessive workloads, the nurses had to prioritize their work, sacrificing "invisible" labour for the more valued visible work (for example, administering medications or discharging a patient). The two areas of nursing practice most affected were emotional work and systems work. Rather than curtail their work in these areas, nurses compensated for unmanageable workloads by donating time. The costs to their own well-being were substantial, manifesting as fatigue, burnout, and moral distress. The invisible features of nurses' work were evident to the nurses themselves only against the backdrop of unmanageable workloads. Further, it must be noted that the nurses (and other health-care providers) did not acquiesce to economically driven directives that jeopardized quality of care. Rather, they acted based on values that were congruent with as well as running counter to such directives, and thus both supported and resisted the directives (Varcoe & Rodney, in press).

The findings of our two studies concerning the invisible costs to nurses are supported by the empirical and theoretical nursing literature. In fact, four decades of research on stress and ethics in nursing points to the fact that nurses have long dealt with excessive workloads (Rodney & Starzomski, 1993). And workload measurement systems, which measure the number and mix of nursing personnel needed to meet care requirements (Giovannetti, 1994, p. 331), have been found to routinely underestimate the actual work of nurses (Armstrong & Armstrong, 1996; Campbell, 1987, 1994; Giovannetti; Storch, 1994). Current research indicates that nurses' workloads and workplaces are becoming even more unmanageable. Nurses' emotional labour, in providing psychological, emotional, and educational support to patients, remains chronically undervalued and notoriously difficult to quantify (Benner, Tanner, & Chesla, 1996; Hiraki, 1998; Liaschenko, 1995; Liaschenko & Fisher, 1999; Nortvedt, in press; Varcoe & Rodney, in press; Yyelland, 1994). While health policy rarely considers the impact of the current climate of health-care delivery on the health and well-

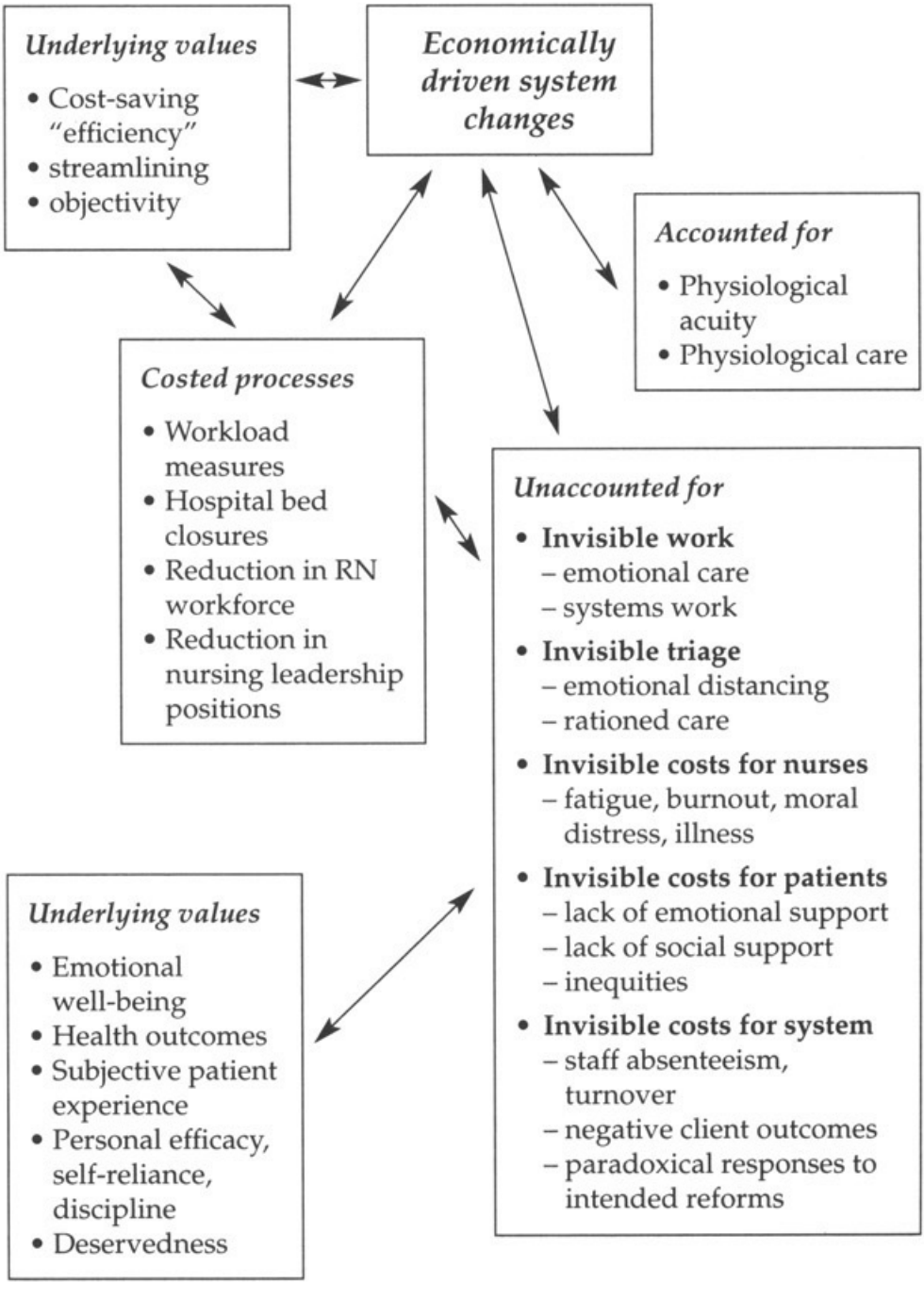
being of nurses, there is mounting evidence of the profound costs in terms of nurses' psychological, social, and physical health (Armstrong & Armstrong; Burke & Greenglass, 2000; Canadian Nurses Association, 1998; Oberle & Tenove, 2000; Picard, 2000; Varcoe, 2001; Varcoe & Rodney; Walters, 1994). Throughout our fieldwork at all four study sites, we were struck by the difficulty faced by nurses in maintaining the standards of their practice and their own well-being.

The consequences for *clients* of nurses' invisible work and invisible triage are even less visible in this era of health-care reform. Nonetheless, it was clear in our studies that clients received less emotional and social support than they and the nurses considered necessary. Also, throughout our fieldwork at all four study sites, clients, families, nurses, and other care providers expressed concern about what was happening to the recipients of care. Disturbingly, it was clear that nurses were often left to compensate for systems inadequacies by rationing care, sometimes based on dubious judgements of social worth. While there is an emerging body of empirical work supporting these findings (e.g., Adams & Bond, 2000; Aiken et al., 2000; Barry-Walker, 2000; Corley & Goren, 1998; Malone, 1996; Mohr, 1997; Mohr & Mahon, 1996; Reynolds et al., 2000; Shindul-Rothschild et al., 1996; Sochalski et al., 1998; Woodward et al., 1998), the evidence is certainly inadequate for a proper evaluation of the effects of health-care reform (including the attendant erosion of the quality of nurses' workplaces) on client outcomes (Aiken et al.; Sochalski et al.). Three leading researchers in the field warn:

> What we know about changes in organization and structure and the potential for those changes to affect patient outcomes pales by comparison to what we do not know. However, this is itself an important finding: we are subjecting hundreds of thousands of very sick patients to the unknown consequences of organizational reforms that have not been sufficiently evaluated before their widespread adoption. (Aiken et al., p. 463)

A growing number of Canadians, ourselves included, believe that the "downsizing," "restructuring," and "re-engineering" that have characterized our health-care system over the past decade have not produced the expected benefits. Our findings indicate that the cost-constraint measures that have been so pervasive in Canada's health-care reform have exacerbated nurses' invisible work and invisible triage, with costs to nurses and clients that are only beginning to be noticed. Perhaps the invisible costs explain, to some extent, the failure of health-care reform to deliver on its promises (see also Figure 1). What does not get noticed cannot be adequately described or measured, and what

Figure 1 *Published Nursing Research on Intimate Partner Violence, 1975–99*



Note: The authors are grateful to an anonymous reviewer for suggesting and providing an initial draft of this conceptual schema. The conceptual schema is *provisional* in the sense that the authors are not making causal claims. Rather, we want to more clearly lay out some of the connections that we have made between concepts in our analysis.

cannot be described or measured will not be addressed as health-care organizations plan and implement changes. Michael Decter, a well-known Canadian health economist, provided an effective metaphor at the 2001 Nursing Leadership Conference held in Ottawa. He stated that the planners of health-care reform a decade ago "built the sail boat but forgot to plan for the wind." Our research indicates that the wind is invisible but powerful. It includes intangibles such as clients' needs for emotional support, families' needs for respite in the care of their chronically ill loved ones, and nurses' needs for access to a supportive network of well-prepared colleagues and practice leaders.

Explicating Values

How can nursing move ahead so as to make visible what has been invisible — or, to use Decter's metaphor, to harness the wind so that it moves us in the desired direction? We see the explication of values as a key.

What gets obscured in nurses' invisible work, the invisible triage processes in which they engage, and the invisible costs to nurses as well as clients are the values that come into play (see also Varcoe & Rodney, in press). For instance, values related to discipline, self-reliance, and personal efficacy underlie nurses' judgements about "frequent flyers"; and values related to clients' emotional well-being, subjective experience, and long-term health underlie concern with their need for emotional and social support. Similarly, values related to cost-saving, efficiency, objectivity, and "streamlining" underlie administrative and policy decisions to reduce professional nursing staff, lay off nurse leaders, close hospital beds or units, and so forth. Given the conflict between these various sets of values and the impact of such values on the well-being of the recipients of care — and on the well-being of nurses — we need a means to explicitly deal with them. Ethical inquiry is a methodology that can help us here:

> Ethical inquiry is an essential part of the philosophy of nursing insofar as it (a) describes *moral phenomena* encountered in the practice of nursing; (b) addresses the basic claims of rights and duties, and goods and *values*, as they arise within the practice of nursing; and (c) assesses the language of rights and duties, and of goods and *values* as a rational endeavor. (Fry, 1992, pp. 93–94; see also Fry, 1999) (emphasis added)

Ethical inquiry is a means not only of analyzing the values that underlie what does and does not get measured, but also of examining the ways in which those values are socially constructed and reflective of broader

social inequities. For instance, a Canadian ethicist, in a value-based analysis of health promotion, warns that regionalization may place "the funding for needed health care in competition with health promotion, often with a budget that is reduced from the original allocation to health care services alone" (Burgess, 1996, p. 160; for other examples see Blue, Keyserlingk, Rodney, & Starzomski, 1999; Sherwin, 1992, 1998; Storch, 1996). Such analyses provide an opportunity for us to critically examine our assumptions so that future policy evaluations will be purposefully based on carefully articulated and ethically defensible goods and values.

Interestingly, philosophers and feminists have called for greater attention to values in economics in general and health-care economics in particular (Donath, 2000; Fuchs, 1996, 2000; Hausman & McPherson, 1993; Hubin, 1994; Weston, 1994). Donath argues that besides the dominant economic story that arises from competitive markets, there is another economic story — one about the production and maintenance of human beings — and that health-care settings are especially important non-household work sites in this "other" economy. She offers the example of the impact on unpaid caregivers (usually women at home) of cost-cutting measures in hospitals. Our research illustrates that this other economy is functioning, albeit invisibly, within the sites of competitive labour markets. It is therefore essential that economic evaluation be preceded by explication of values, if this entire other economy — whether in the home or in the hospital — is not to go uncounted.

Let us close by illustrating how ethical inquiry might support economic inquiry in nursing practice. The nurses with whom we worked in the two emergency units and two medical units were clearly distressed about the staffing allocations of professional nurses in their workplaces. Also, objective measurement tools such as workload indexes — if such tools were used at all — failed to capture their invisible work. Yet the staff nurses reported that they had no say in staffing decisions. What if staff nurses themselves articulated the elements of their work (both readily visible and less visible), in partnership with administrators and policy-makers, so as to provide a more meaningful basis for quantitative and qualitative evaluation of resources? What if all these players explicitly discussed the values they held regarding care? And what if staff nurses — nurses on the front lines of patient/client, family, and community care — actually had a meaningful say in subsequent health-policy decisions? For instance, what if they were able to influence the ratio of nurses to patients? Such initiatives, whether part of a participatory action research project or a health-care agency mandate, could go a long way towards improving the ethical

climate for nursing and interdisciplinary practice (Breda et al., 1997; McGirr & Bakker, 2000; Peter, 2000; Robinson, 1995; Street, 1998). Explicit ethical inquiry in such initiatives would help those involved to bring workplace values into the open, strive for equitable allocation of resources, and reflect on the kinds of societal changes required to rethink our values concerning nursing care and the vulnerable recipients of that care.

Perhaps most importantly, explicit ethical inquiry would help us to realize that the active involvement of frontline nurses in changing their conditions of work is a moral imperative in health-policy work. Health-policy formulation is not morally neutral. It has, in the words of Malone (1999, p. 18), an "irreducibly moral dimension." Nursing must come to terms with the fact that health policy has evolved in ways that overlook critical elements and compound the invisibility of nursing work (Health Canada Office of Nursing Policy, 2000). If it does not, nurses will continue to be seen as merely a commodity, and quality as merely a product of adequate supply. We must, as a profession, develop and demonstrate our expertise in ethical as well as economic inquiry. Our goal should be "to help put into the public space of language a role for human beings that is not merely based in market productivity but in having a socially meaningful and morally coherent life and death" (Malone, 1999, p. 21). As we indicated at the outset of this paper, those of us engaged in economic as well as ethical inquiry should continue to work towards a system that is more humane as well as more effective and efficient for all those involved in health-care delivery.

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Designer's Corner

Willingness-To-Pay (WTP): The New-Old Kid on the Economic Evaluation Block

Amiram Gafni

Cost-benefit analysis (CBA) is defined in the methodology literature as a form of economic evaluation whereby both costs and consequences are measured in monetary terms (Drummond, O'Brien, Stoddart, & Torrance, 1997). In recent years we have witnessed renewed enthusiasm for CBA and contingent valuation (CV) methodology, in particular the willingness-to-pay (WTP) approach to measuring the consequences of health-care programs (Diener, O'Brien, & Gafni, 1998; Klose, 1999). This renewed enthusiasm stems partly from the congruence between the empiric method used to measure the outcome (i.e., WTP) and the theoretical foundation of CBA in welfare theory (Mishan, 1971). This type of analysis also enables direct comparison of benefits and costs, as the two are measured in the same units. An added attraction of CBA is that the same principle of net benefit (i.e., benefit minus cost) can be applied to other sectors such as transport or environment, permitting intersectoral comparisons of resource use.

The maximum amount that an individual is willing to pay for goods or services is a common economics measure of the value of those goods or services to the individual. Yet only in recent years have we witnessed renewed enthusiasm for the use of WTP survey techniques in estimating monetary values for improved morbidity and mortality risks. As was observed as far back as a decade ago (Johannesson & Jonsson, 1991), environmental economics and health economics developed differently with respect to evaluation methods. While CBA (and WTP) has evolved into the most common method for valuing environ-

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mental benefits (including those related to health outcomes), health economics has developed in the direction of cost-effectiveness and cost-utility analysis. Furthermore, it is safe to say that CBA is the most common method of economic evaluation in all other content areas (e.g., transportation, agriculture).

Despite renewed enthusiasm for the WTP technique in health-care applications, there remain objections, resentment, and scepticism regarding its desirability and feasibility. The objections can be classified into four categories: theoretical; based on feasibility of measurement; based on misunderstanding of economic concepts; and emotional. My purpose here is to provide a *brief* review of the measure, describe a new instrument for the measurement of individual WTP, and respond to some of the criticisms raised. It is my hope that readers will be tempted to learn more about what I consider to be a very useful tool for evaluating health-care programs.

It should be pointed out that even though the question posed might vary little (e.g., what is the maximum amount the person is willing to pay for health-care products, programs, or improved well-being), one must distinguish among the uses to which the information will be put. One potential use is pricing and demand studies (e.g., market research). For suppliers of health-care goods and services in private markets, for example, forecasts of consumer demand as a function of price are valuable inputs to pricing and marketing decisions. We are not interested in this application here. We are interested in the use of WTP in the context of CBA. The question that CBA sets out to answer is whether a given number of health-care programs should be undertaken at all, and, if funds are limited, which programs among those predicated to generate surplus of benefits over costs should be selected. The focus of CBA is typically benefits produced and forgone in the economy as a whole — that is, the welfare of a defined society.

The rationale for economic evaluation arises from the economic concept of opportunity cost. Allocating scarce physical and human resources to an influenza vaccination program, for example, means forgoing the opportunity to use those resources in other welfare-enhancing ways. In this context, Williams (1983) defines economic evaluation as the process of "ensuring that the *value* of what is gained from an activity outweighs the *value* of what is sacrificed." The WTP approach is a method for measuring an individual's valuation of a program by asking that individual how much he or she is willing to pay (i.e., sacrifice) to have the program introduced. The alternative approaches of

time trade-off (TTO) and standard gamble (SG) are also based on the notion of sacrifice that underlies the opportunity-cost concept. However, WTP offers several advantages over these approaches, as will be described below.

Gafni (1991) and later O'Brien and Gafni (1996) suggested conceptual frameworks, involving a list of questions and considerations, to help in the interpretation or design of WTP studies in health care. Upon reviewing the considerations, the advantages of the WTP approach become apparent. Let me mention a few. The WTP technique can be modified to reflect the unique nature of health as a good and the market for health care. From the perspective of the individual, for example, the outcome of any health-care intervention is probabilistic. Hence the measurement of an individual's valuation of potential outcome must capture their attitude towards risk. Also, it has been shown that, in the case of health-care programs, outcomes are intrinsic to the individual and cannot be distributed among individuals. Hence social decision-making should also incorporate the individual's attitude towards risk (Ben-Zion & Gafni, 1983). Another distinguishing characteristic of the health-care market is unpredictability of personal demand. The institutional response to this uncertainty is the development of insurance (public or private). When the services provided are financed through an insurance (or taxation) mechanism, the WTP question should be adapted accordingly.

WTP is the only measure that can capture externalities — that is, one person's health status may affect another person's health status (e.g., transmission of tuberculosis) or utility (e.g., the case of compassion). The role of externalities is much more applicable to health-care consumption than to consumption of most other commodities. Hence when such effects exist, they should be included in the analysis when appropriate. Because the outcome is measured using monetary units (e.g., $), WTP allows for direct cost-benefit comparison to determine the net benefit of the program. And because the same principle of net benefit can be applied to other sectors, such as education, transport, or the environment, intersectoral comparisons of resources can be made. None of these various comparisons are possible with other forms of economic evaluation. WTP also allows the individual to trade poor health for other commodities and does not restrict "sacrifices" to the domain of health (e.g., years of life in the TTO technique and risk of death in the SG technique). Finally, WTP is the most sensitive measure of outcome, as it does not make arbitrary assumptions about the indi-

vidual's preferences. For example, it allows an individual to reveal a preference for the short-term (say, 1 hour) reduction of severe pain.

As we have seen, the objections to WTP fall into several categories. Theoretical objections stem mainly from use of the neoclassical conceptual framework of welfare economics, also known as the welfarist approach, as the foundation for economic evaluation. In economics, when dealing with issues of resource allocation one usually begins by choosing an analytical framework to guide the analyses of the welfare consequences of a change in allocation. Thus the role of the welfarist approach in defining the proper methodology (and hence methods of measuring the costs, consequences, and decision rules) is a fundamental one in this field. The welfarist approach still dominates in economics. However, the longer we have a theoretical framework the more we will find out about its shortcomings and attempt to develop new approaches. The development of a new theoretic approach is unfortunately not an easy task, however, as can be seen from recent attempts. Like others (e.g., Weinstein & Manning, 1997), I believe that the debate about the proper conceptual foundation is not yet over and thus should be the focus of future research.

The WTP approach is not without problems, the recognition of which underlies the reluctance of some researchers to use it. It is important to note that many of these problems are *not specific to WTP* but are common to — though not usually acknowledged in — research that adopts alternative approaches to measuring individual valuations of a program. A typical criticism is the hypothetical nature of the question and the compensation mechanism. It should be mentioned that the hypothetical nature of the sacrifice is common to all types of measure (e.g., trading off years of life in the TTO measure or increased risk of death in the SG measure). The advantage of WTP is that although the exercise may be hypothetical, in that individuals are not required to make the payment implied in their responses, the "medium" through which the evaluation is expressed (i.e., payment) is one that individuals are already accustomed to on a daily basis. This cannot be said of trading years of life or risks of death.

I recently labelled one group of objections to the WTP approach as "emotional" (Gafni, 1998). Such objections are widespread but are difficult (or even impossible) to precisely define and quantify. They are nicely described by Weinstein and Manning (1997): "The major disadvantage of the benefit cost framework is the requirement that human lives and quality of life be valued in monetary units. Many decision

makers find this difficult or unethical or do not trust analyses that depend upon such valuations"; "Despite the implications of economic welfare theory, a number of members of the panel on Cost Effectiveness in Health and Medicine were unwilling to accept the equivalence of putting time costs in dollar terms in the numerator and subtracting the time from the QALYs [quality-adjusted life-years] in the denominator. Others were unwilling to value time costs at different rates for different groups." The latter quote illustrates vividly that individuals who are willing to accept the welfarist approach as the conceptual foundation for the analysis (i.e., the main source of the theoretical objection to WTP) may not be willing to accept the implications in terms of how one should measure costs and consequences (valuation of "time costs").

Furthermore, emotionally based objections are often vague and are not supported by evidence. For example, there is no evidence (e.g., survey of decision-makers) to support the argument that decision-makers find WTP unethical or difficult to conduct and do not trust analysis that values human lives and quality of life in monetary terms. Decision-makers (governments included) encourage and sometimes mandate the measurement of human lives and quality of life in monetary units in the context of CBA in areas such as transportation and the environment. It is not clear why the same decision-makers will not accept such valuations concerning health care.

With respect to the criticism about validity and feasibility, I agree with Kenkel (1997) that measurement methods have improved and that the practical experience gained from measuring QALYs has been used in some cases to advance the WTP measurement process. An example of a new WTP measurement instrument is the modified decision board (for details, see Gafni, 1997), a visual aid to help clinicians present information to their patients in an efficient and standardized manner. This method was first suggested by Levine, Gafni, Markham, and MacFarlane (1992) and used successfully to improve communication between doctors and patients in the case of adjuvant chemotherapy for early-stage breast cancer. Decision boards have since been developed and employed successfully with other patients at the point of decision-making. They have been modified to serve as WTP instruments and have been successfully used in research (Matthews, Birch, Gafni, & DiCenso, 1999; O'Brien et al., 1998). We recently used a computerized version in a study of dental care and found it to be very satisfactory. It is my belief that this "new-old" kid on the economic evaluation block has a great future.

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Translating Research

The Costs and Effects of Addressing the Needs of Vulnerable Populations: Results of 10 Years of Research

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Concepts of Vulnerability

Vulnerability in an individual implies "inequality" in the person's biological characteristics (age, gender, genetic endowment), personal resources (cognitive, emotional, intellectual), and/or environmental supports (social, material, cultural). While biological characteristics cannot be modified, personal resources and environmental supports can, and to considerable economic effect (Browne, Roberts, et al., 1999).

Within an individual, aspects of vulnerability intersect, as shown in Figure 1, and can be synergistic and cumulative, such as "young gay Asian man with HIV/AIDS who is on social assistance."

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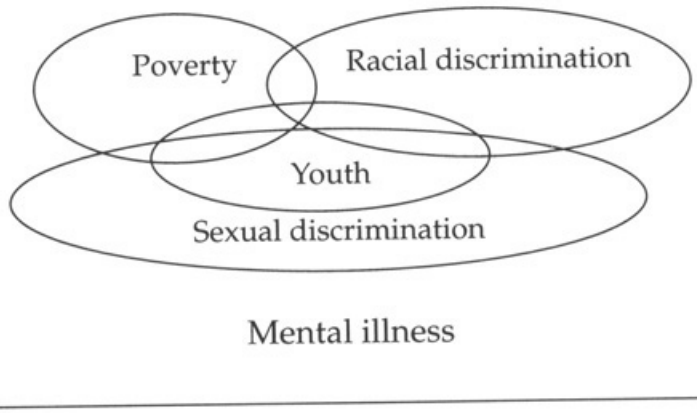
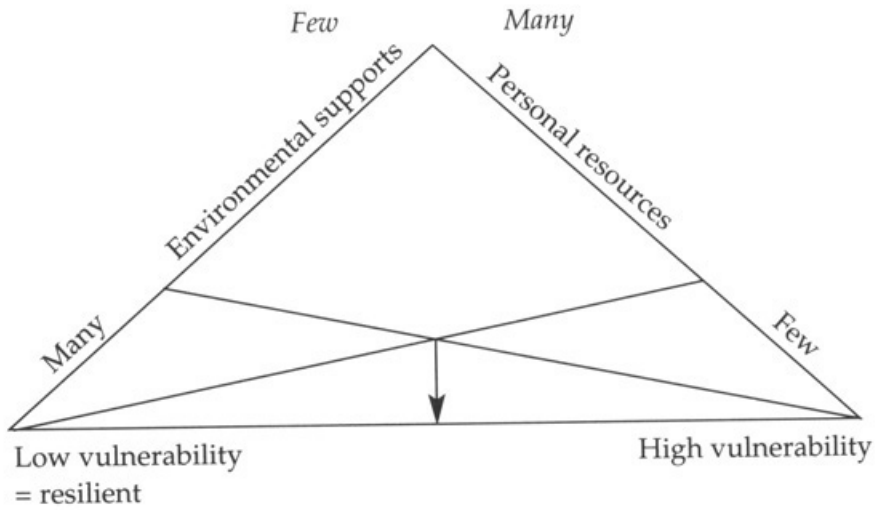
Figure 1 *Intersection of Spaces of Vulnerability*



Source: Delore & Hubert, 2000

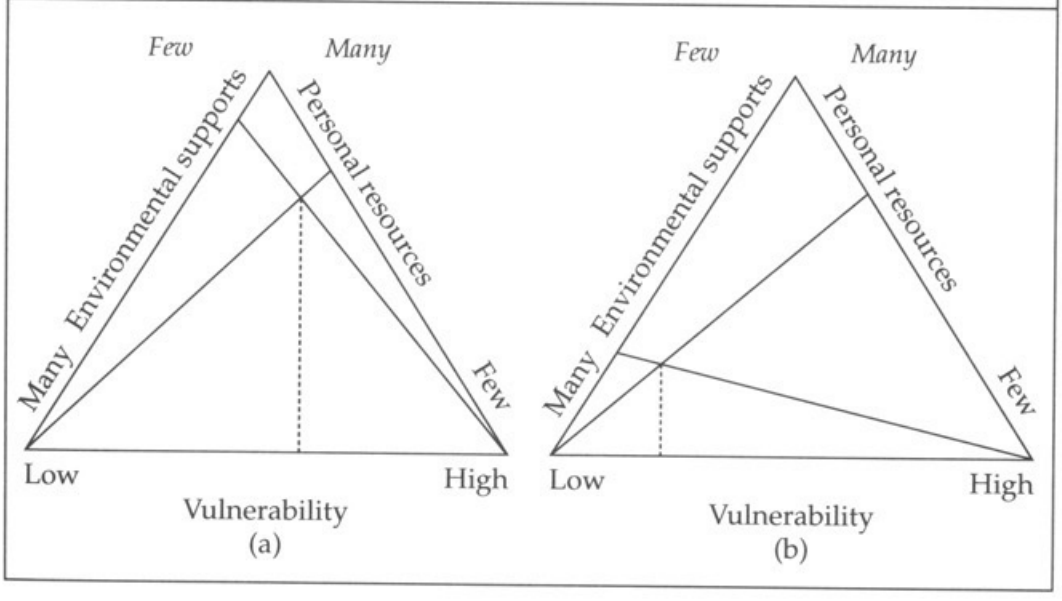
In a vulnerability index (Rogers, 1997), vulnerability is the net result of an interaction between personal resources and environmental supports, both of which, along with genetic endowment, are determinants of health and therefore of expenditures on health services. Figures 2 and 3 show that even if personal resources hold constant, variations in the individual's environmental supports can greatly alter their degree of vulnerability, and thus also their use of services. Furthermore, insured medical services may not meet all of the sources of vulnerability.

Figure 2 *Concept of Vulnerability*



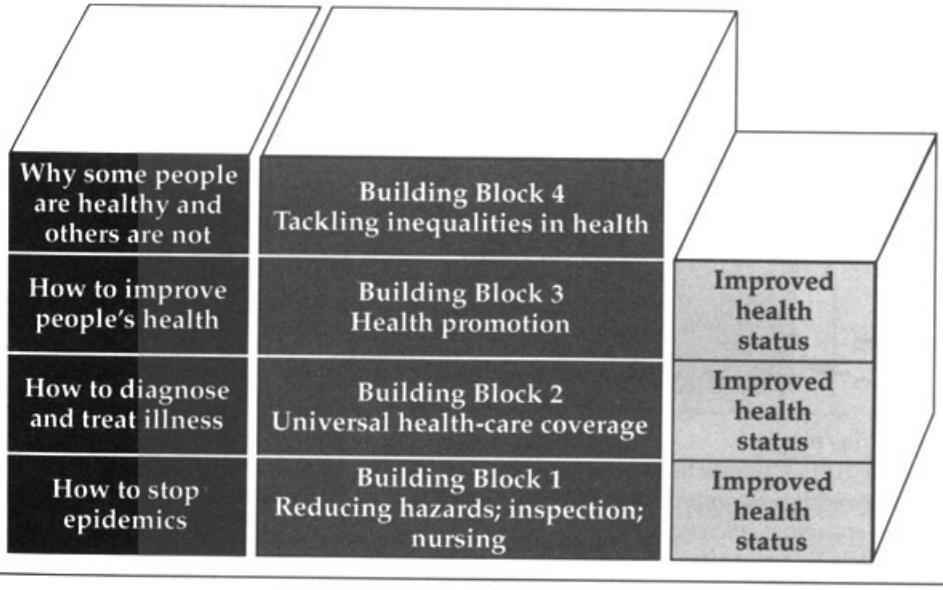
Source: Rogers, 1997

Figure 3 *Degrees of Vulnerability*



The work of the System-Linked Research Unit on Health and Social Service Utilization at McMaster University in Hamilton, Ontario, addresses such health inequalities and documents the reasons why some people with a particular disease or condition are healthier and less costly to the system than others (see Glouberman's [2001] fourth building block of health policy in Figure 4).

Figure 4 *Building Blocks of Health Policy*



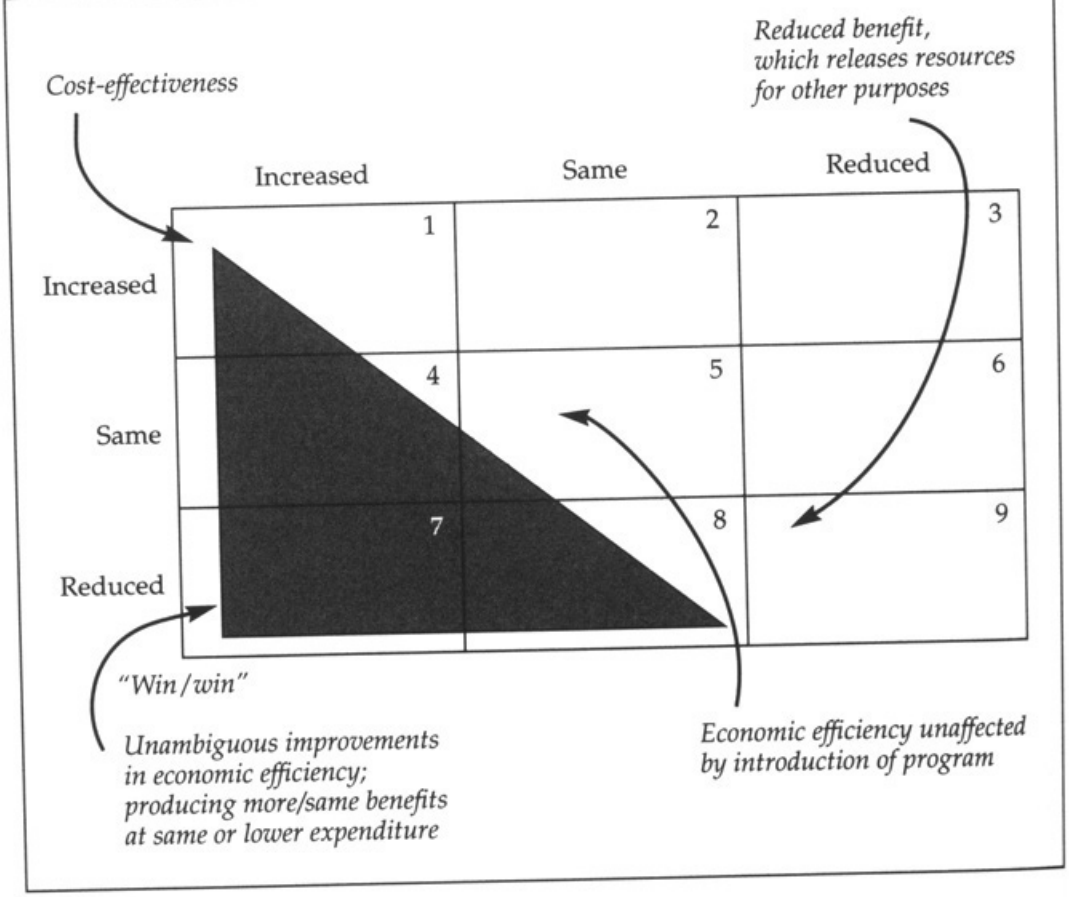
Source: Glouberman, 2001

We will attempt in this article to briefly summarize 10 years of research on the results and costs of efforts to reduce inequalities in a variety of vulnerable populations. We argue that, in a system of national health insurance, measures to reduce inequalities will pay for themselves within a year, and that health-care costs can be reduced by simply helping people to get the services they require. The most expensive services we now provide are those that are *not* tailored to people's needs (vulnerabilities).

Evaluation of Costs and Effects

Although the literature contains many evaluations of programs seeking to achieve improved outcomes for vulnerable populations, few of these outcomes studies include measures of costs. The work of the System-Linked Research Unit and its community partners — service providers for the regions of Halton and Hamilton-Wentworth — can make a significant contribution to our understanding of this issue.

Figure 5 *Economic Evaluation of Health-Care Programs*



As depicted in Figure 5, the economic evaluation of health-care programs yields nine possible outcomes (the more favourable ones are highlighted by shading) (Birch & Gafni, 1996). In outcome 1, increased health benefits are achieved through increased expenditures on resources. Cost-effectiveness results when increased benefits are achieved through increased expenditures, typically among marginalized populations with low access to services. The outcome is also favourable when increased benefits are achieved through the use of one approach over another at equivalent cost. Outcome 7 represents a "win/win" situation, or unambiguous improvements in economic efficiency, when more benefits are achieved at lower cost, especially in populations who consume many uncoordinated services. Outcome 8 represents a situation of alternative health programs achieving the same effect. However, some approaches are associated with lower expenditures from a societal perspective. Often, studies that find no difference in the effects of two approaches miss the real effect: reduced use of services with one of the approaches. Outcomes 7 and 8 are superior to the more frequently encountered outcome 9, where funding cuts are accompanied by a potential reduction in benefits. In these two outcomes, resources are released for use in other areas (Birch & Gafni).

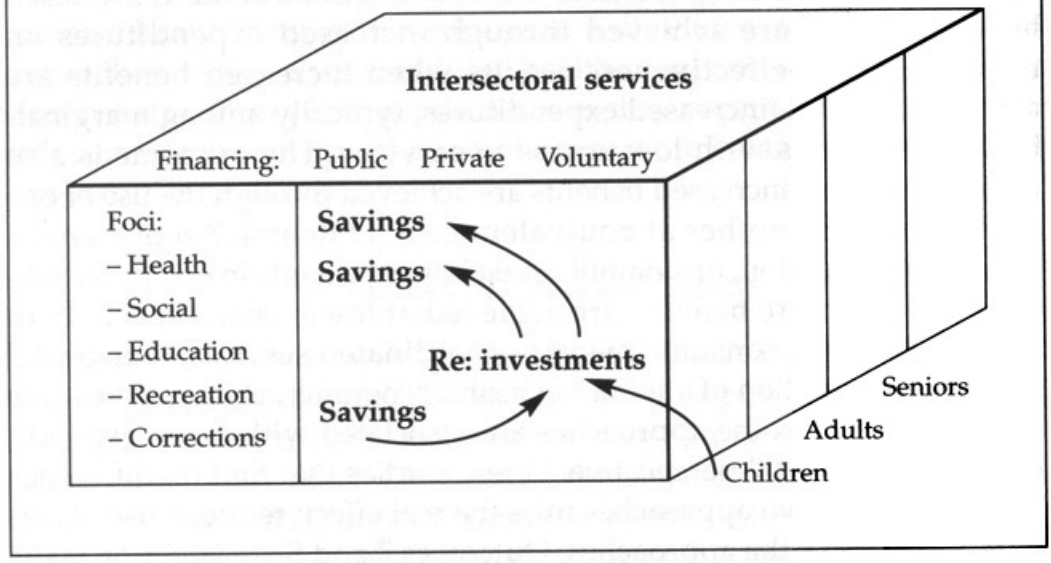
This approach can be used to classify the main effects and costs of comparable community health interventions. It can also be used to classify the recipients of various health interventions according to degree of beneficial results, as well as the expenditures necessary to achieve these results. Within national health insurance systems, people tend to use whatever services are available, even if they are not necessarily appropriate (Browne et al., 1995).

Finally, it has been found that investments in one sector can achieve savings in another — such as recreation provided by the voluntary sector resulting in savings to the publicly funded health, social, and corrections systems (Browne et al., 2000; Browne, Byrne, et al., 1999; Browne, Bryne, Roberts, Gafni, & Whittaker, in press; Browne, Roberts, et al., 1999). (Nonetheless, agencies should be compensated for savings they generate elsewhere [Browne et al., 1995]).

Research Production and Utilization

Over the past 10 years, the System-Linked Research Unit has been studying how improved health and cost containment might be achieved by providing community-based services to people with some health problems and exhibiting many signs of vulnerability (Browne, Roberts, et al., 1999). With the active participation of our community

Figure 6 *Societal Savings Resulting from Strategic Investments*



partners, the Unit's investigators have conducted studies on a variety of samples, settings, sectors, and services in an effort to reduce inequalities. The findings are relevant for the participating agencies and, since they have been involved, dissemination of the findings is easy. At the same time, agencies are more likely to use their own relevant information once it is made understandable.

What we have found is both simple and profound: that helping people to find the means to feel better and function more effectively costs no more, in a system of national health insurance, than doing nothing.

Why? Because people who are hurting will usually try to find a remedy, yet the services they use are not necessarily the ones that will solve their problem. A piecemeal approach to helping them can be expensive and still fail to identify the cause of the problem (Browne et al., 1994). Even a trained professional will have difficulty sorting out the differences among a person's condition (say, severe diabetes), circumstance (recent job loss), challenges (depression), and context (a child in trouble with the law).

Savings can be achieved not because an effective service is cheap, but because making people healthier and better able to cope with their life circumstances results in savings elsewhere. The greatest cost savings in health care tend to accrue among those people who are high users of the health-care system.

What may seem unlikely on the surface — better health outcomes for the same amount of money or less — actually makes perfect sense. Consider someone who has a chronic illness, lives alone, and is having trouble coping. If there is no concerted effort made to help this person with problem-solving and adjustment to his or her particular circumstances, the individual will likely spend a great deal of time seeking assistance from a variety of insured services. We compared two groups of people with chronic illness, poor adjustment, and poor problem-solving ability. One group received counselling and support and the other group were left to their own devices. The group who struggled with poor coping skills on their own were half as well adjusted and cost the health system 10 times as much as the other group ($40,000 vs. $4,000/person per year) (Roberts et al., 1995).

We found similar patterns in other areas. Some studies found improved outcomes for higher expenditures, but these were in areas in which the clients were members of an under-served group such as a minority population (Majumdar, Browne, Roberts, MacLean, & Carpio, 1995), family caregivers of individuals losing their mental capacities to a condition such as Alzheimer disease (Milne, Sacco, Centinski, Browne, & Roberts, 1994), or persons with chronic schizophrenia living in municipal lodges (Byrne et al., 1999).

The System-Linked Research Unit received core funding from the Ontario Ministry of Health and raised funds for specific projects from other sources, including the federal government. We approached the comparative costing of services on a much broader scale than usual. We looked at not just the cost of providing the service to achieve a certain outcome, but also the other services the person accessed in trying to cope with their particular condition or problem. We used an inventory to track direct and indirect costs, including the frequency of their visits to the doctor or hospital, the medications they used, and whether they were on social assistance (Browne, Arpin, Corey, Fitch, & Gafni, 1990).

One study looked at a program for screening seniors over 75 years of age and living alone and then treating those who were suffering from loneliness and isolation. The study found that those who received support showed some social/emotional improvement and consumed less than one third the health-care resources of the untreated group (Hay et al., 1998).

Another study found that people who attended a clinic for chronic pain increased their ability to live with their pain and, when compared to an equivalent group who did not attend a pain clinic, generated a

proportionate decrease in costs associated with use of other health services (Weir, Browne, Tunks, Gafni, & Roberts, 1992).

In yet another study, clients treated at a mental health clinic were found to have similar states of mental health as clients who were referred to the clinic but did not use the service, yet clinic users consumed fewer other health-care services by far (Emond & Browne, 1992).

The research also taught us a great deal about the kinds of services that produce improved health at the same or lower cost. Our current health-care system is geared to offering services one provider at a time, one problem at a time, and on demand. The System-Linked Research Unit has found the most successful strategies to be those that are:

- cooperative and cross-sectoral, linking physical health care to social services, mental health services, and other services
- comprehensive and holistic (rather than disease-by-disease), treating the whole person or the whole family in context
- proactive, reaching out to those who are unlikely to find the help they need on their own.

The services that produced improved health outcomes were not necessarily medical services (Browne et al., 1995). Some were delivered in a doctor's office, but others were provided by a nurse in the person's home (Roberts et al., 1999), or by a volunteer at a seniors' centre, or by a therapist at a mental health clinic, or by a children's recreation coach at a neighbourhood park (Browne, Byrne, et al., 1999), or by a psychologist in a school.

Canadians are proud and protective of their health-care system, and so they should be. We would argue, however, that investments in non-medical services that support health and well-being would take pressure off the health-care system and help the medical community do what it does best.

One suggestion would be to invest in more social workers for hospital emergency rooms. Emergency doctors do not have the time to determine what is troubling people who arrive in the middle of the night; their job is to deal with medical crises. Yet someone who is battling cancer may go to the emergency room mainly because they are frightened and alone. A home assessment, arranged by a social worker, for community counselling and support services could make a major difference to that person's recovery. Based on our research, a community service such as this would pay for itself through cost savings elsewhere in the system. However, we have to give the hospitals and com-

munity agencies the funding they need to provide the services that will save money for the system as a whole (Browne et al., 1994).

The cost savings we found were not always in the health-care budget, but they often were. People who had been relying heavily on health services used fewer of them, or fewer expensive ones, when their needs were not met appropriately. Sometimes, the savings were in social services, or in the tax system when people became well enough to return to work (Browne et al., 2000).

Another of our studies looked at a program for very troubled adolescents provided by an alliance of health, social, and educational service providers in a school setting. It compared the cost of the program to the cost of hospital and specialist care for teens who were waiting for admission to the program. Over the same period, the latter group had poorer emotional health and twice the cost ($10,000/person per year) of the students enrolled in the program (Pallister, Browne, Roberts, Byrne, & Gafni, 1995).

A study of single parents on social assistance found that those who were offered a coordinated package of services — child care and recreation for their children, job training, and visits by a public health nurse — were more likely to leave welfare for work than those offered one piece of the package or those left to fend for themselves (Browne et al., in press). The package cost no more than the piecemeal services consumed by those left to fend for themselves and was associated with a $300,000 savings in social assistance payments within 1 year for every 100 mothers served. Recreation for the children paid for itself in reduced use of professional and probationary services as well as resulting in mental health benefits for their mothers (Browne et al., 2000). A number of municipalities in the province of Ontario are improving their services to families on social assistance, based on these findings.

The most serious barrier to the delivery of cooperative, holistic, proactive community-based services is separate funding of the various sectors. Ways must be found to reward alliances among the health, social, education, recreation, and corrections sectors.

We are not saying that developing these strategies and alliances will be easy. We are saying that innovative, intersectoral approaches have the potential to save precious public resources, not only in health care but across publicly funded systems, and at the same time to improve the quality of people's lives.

In summary, our work demonstrates that community-based services are more effective and less expensive when they are proactive,

comprehensive, and aimed at reducing the inequalities in coping capacity and social resources that result in ill health.

The System-Linked Research Unit is currently testing, via randomized trials, the value of augmenting homemaking services with a nurse assessment. It is hypothesized that clients who receive the assessment will show less deterioration and use of services (Markle-Reid et al., 2000; Weir et al., 1998). The added cost would be made up by decreased use of other services.

Another trial is underway to test the value of home care versus use of nurse clinicians in a shopping mall. It is hypothesized that clients who attend the mall clinics will demonstrate improved health status and that the cost of this approach will be one quarter that of home care (Van DeVelde-Coke, McGlashan, Browne, Gafni, & Roberts, 2000).

Both of the hypotheses in ongoing studies would be examples of a "win/win" outcome from an economic perspective.

The Happenings section in this issue of the Journal provides further examples of economic evaluations currently underway.

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Happenings

Focus on Health-Care Settings: The Home Care Evaluation and Research Centre

Denise Guerriere, Patricia McKeever, and Peter Coyte

Health system restructuring in Canada has involved a dramatic shift towards the delivery of ambulatory, home-based, and, more recently, Internet-based health care. This dispersion of health-care services represents one of the most significant social changes of the last two decades and will continue to have major repercussions in the new century. Although restructuring has been rapid and ubiquitous, systematic economic evaluations of non-traditional health-care services and delivery settings have been lacking in Canada. This absence of evidence limits opportunities to measure effectiveness and impedes decision-making.

To fill this gap, the Home Care Evaluation and Research Centre (HCERC) was launched in 1998 at the University of Toronto, with public and private sector funding of more than $1.2 million. HCERC's Co-Directors are Patricia McKeever (Faculty of Nursing) and Peter Coyte (Department of Health Administration, Faculty of Medicine). HCERC's goals are to facilitate collaborative research related to the settings where health care is sought, delivered, and received, and to support knowledge transfer and linkage activities throughout the research process.

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HCERC's growing research and stakeholder community addresses the organization, delivery, and financing of health care across diverse settings and sites. Currently, 26 research projects have been funded to a total of over $6 million, with further funding pending. HCERC research is multidisciplinary in scope (e.g., health economics, health administration, nursing, epidemiology, political science, geography, law, sociology, physiotherapy, occupational therapy, engineering, and medicine) and collaborative in design. Its focus areas have included utilization and uptake issues, funding, human resources, technology, home-based service provision, cost-effectiveness, and policy design. Recently funded economic evaluation projects include:

Evaluation of the Ambulatory and Home Care Record (AHCR), by Denise Guerriere, with Peter C. Coyte, D.E. Tullis, Wendy J. Ungar, and Mary Corey. The main purpose of this study is to evaluate the reliability of the AHCR with adults who have cystic fibrosis. The secondary objectives are to measure the economic burden associated with care for CF patients through the use of the AHCR, and to assess the sensitivity of resource cost estimates to alternative methods of valuing patients' and informal caregivers' forgone time. This study is funded by the Canadian Institutes of Health Research. The project timeline is 2 years, from 2000 to 2002.

Evaluation of the Chronic Pain Self-Management Program, by Sandra Lefort and Judith Watt-Watson, with Katherine Gray-Donald, Karen Webber, Peter C. Coyte, and Denise Guerriere. The purpose of this randomized clinical trial is to evaluate the feasibility and cost-effectiveness of a community-based chronic pain self-management intervention delivered by multiple nurse facilitators in two provinces. This study is funded by the Canadian Institutes of Health Research. The project timeline is 3 years, from 1999 to 2002.

At Home Early Discharge (AHEAD) Program for Hip Fracture Patients, by Susan Jaglal, with Peter C. Coyte, Hans Kreder, Gary Naglie, and Joseph Schatzker. The purpose of this randomized controlled trial is to evaluate the cost and effectiveness of a community-based early-discharge program for hip fracture patients. This project is funded by the Canadian Institutes of Health Research. The project timeline is 3 years, from 1998 to 2001.

Cost Effectiveness of Home Versus Hospital Support of Breast Feeding in Neonates (Substudy #12 of the National Evaluation of the Cost-Effectiveness of Home Care), by Bonnie Stevens and Patricia McKeever, with Peter C. Coyte, Stacey Daub, M. Dunn, Denise Guerriere, Sharyn Gibbins, J. MacDonell, and Arne Ohlsson. The objective of

this randomized control trial was to analyze and compare the cost, safety, and efficacy of supporting breastfeeding in hospital and home settings for term and preterm neonates. This recently completed project was funded by the Health Transition Fund of Health Canada and The Hospital for Sick Children Foundation, from 1998 to 2001. Information on the project will soon be available on the HCERC Web site.

Costs and Outcomes of an Integrated Community Care Pathway for Post Myocardial Infarction Patients, by Peter C. Coyte and Linda Cash, with Wendy Young, Susan Jaglal, Sean Goodman, George Rewa, and Dave MacPherson. The research team developed, implemented, and evaluated the costs and outcomes of an integrated community-care pathway for post-myocardial infarction patients in an ethnically diverse population. This recently completed project was funded by the Health Transition Fund of Health Canada, from 1998 to 2000. Information on the study is available on the HCERC Web site.

To learn more about the HCERC research community, please visit <www.hcerc.utoronto.ca> or contact Kelly Murphy, Manager of Knowledge Transfer & Administration. Telephone: 416-946-5958. E-mail: <k.murphy@utoronto.ca>.

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Evaluation of a Weekend Respite Program for Persons with Alzheimer Disease

JoAnn Perry and Kymberley Bontinen

Dans un contexte où les besoins des prestataires de soins familiaux demeurent insatisfaits, la sous-utilisation documentée des programmes de soutien moral génère des interrogations. Cette étude avait pour objectif l'exploration du vécu des prestataires de soins familiaux en rapport à un programme pilote de soutien moral qui offre des soins pendant les week-ends aux personnes atteintes de la maladie d'Alzheimer ou de la démence qui s'y rattache. L'approche d'évaluation sans objectif a permis de recueillir les réactions de 18 prestataires de soins familiaux face à un programme pilote qui a été mis sur pied par un organisme communautaire œuvrant en soins infirmiers. Une analyse de contenu des entrevues menées auprès des prestataires a permis d'identifier trois catégories : la capacité que possède une prestataire à prendre soin d'elle-même, la sécurité du membre de la famille ainsi que son bien-être. Les résultats obtenus suggèrent l'existence d'un lien entre le soutien dont bénéficie la prestataire de soins familiaux et la sécurité et le bien-être dont jouit le membre de la famille. La perception des prestataires concernant les coûts et les bénéfices générés par le soutien influence la fréquence à laquelle elles ont recours aux services dispensés dans le cadre du programme. Les conséquences en matière de recherche font l'objet d'une discussion.

The documented under-use of respite programs in the face of unmet family caregiver needs is puzzling. The purpose of this study was to explore family caregivers' experience with a pilot respite program of weekend care for persons with Alzheimer disease (AD) or a related dementia. The goal-free evaluation approach captured the responses of 18 family caregivers to a pilot program developed by a community nursing organization. A content analysis of the caregiver interviews identified 3 categories: caregiver self-care, relief for the caregiver, and safety and comfort of the family member. The results suggest a link between the family caregiver achieving respite and the safety and comfort of the family member. The caregivers' perspective regarding the costs and benefits of respite influences the frequency with which they use the program. Research implications are discussed.

The Canadian Study of Health and Aging (Canadian Study of Health and Aging Working Group [Canadian Study], 1994) reports that 8% of the population aged 65 and over and 34.5% of the population aged 85 and over are diagnosed with dementia. Alzheimer disease (AD) is the most frequently diagnosed type of dementia included in these figures.

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As the number of people with dementia increases so too does the work of the family, since family members often provide care to persons with dementia at some point during the course of the disease (Baumgarten, Battista, & Infante-Rivard, 1992; Keady, 1996; Kuhlman, Wilson, Hutchinson, & Wallhagen, 1991). The median length of time spent caring for people with AD is 6.5 years (Haley, 1997). Of all family caregivers, women are the largest group, while spouses are the first in the family to take on the caregiver role (Abel, 1990; Coward, Horne, & Dwyer, 1992; Haley; Pruchno, & Resch, 1989; Stone, Cafferata, & Sangl, 1987). This paper reports on an evaluation of a respite program for families seeking relief from caregiving duties.

Currently there is no reason to suggest that dementia will recede as a major concern until researchers identify some causal variable that is amenable to intervention (Canadian Study, 1994). Thus, persons with dementia and their family caregivers pose a considerable challenge for Canadian nurses who encounter both in numerous settings.

As research has established, stress and burden are among the more frequently identified consequences of caregiving, especially if the care recipient has dementia (Miller & McFall, 1992; Robinson, 1990; Zarit, Todd, & Zarit, 1986). Other consequences are depression (Baumgarten et al., 1992; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Parmelee, 1992), insomnia, and anxiety (Baumgarten et al.; Pushkar Gold et al., 1995; Robinson & Steele, 1995).

In contrast to the negative aspects of caregiving, a small but significant body of research has identified rewards and points of satisfaction. Caring for a loved one may become an integral part of one's identity and provide opportunities for one to demonstrate commitment and reciprocity (Cartwright, Archbold, Stewart, & Limandri, 1994; Guberman, 1999; Morgan & Laing, 1991). Currently there is no model or theory for evaluating the relationship between positive and negative consequences of caregiving. In both practice and research, caregiving is recognized as a mixture of positive and negative outcomes because it is a complex process involving long family histories.

The family caregiver's need for assistance and support in the form of respite is recognized in the literature, but respite has had mixed results in terms of demonstrating effective outcomes (Guberman, 1999; Homer & Gilleard, 1994; Knight, Lutzky, & Macofsky-Urban, 1993; Shantz, 1995). As an intervention, respite is compelling to practitioners and researchers because of caregiver interest and demand, and is con-

fusing because even when made readily accessible it remains underused. In this paper, we present findings from a pilot respite program and describe the family caregivers' overall experiences with it. We discuss the identified caregiver categories in an effort to enrich our understanding of the respite experience.

Literature Review

Inconsistencies in definitions and conceptualizations plague the respite literature (Strang & Haughey, 1998). Respite programs differ in structure and function and in terms of desired and expected outcomes (Smyer, 1999). Most research studies and literature reviews provide operational definitions that include caregivers leaving their kin with an informal (volunteer) or formal (paid) care provider (Rudin, 1994; Smyer; Theis, Moss, & Pearson, 1994; Worcester & Hedrick, 1997). These definitions also include the location (in-home or institutional) of the respite as well as the length of the stay (Rudin).

Some authors claim that respite is a unique intervention from which both the caregiver and the client derive benefits (Rosenheimer & Francis, 1992; Strang & Haughey, 1998; Theis et al., 1994). Other studies describe respite as prolonging a care recipient's ability to remain in his or her own home and thus delaying long-term placement (Kosloski & Montgomery, 1995; Lawton, Brody, & Saperstein, 1989; Rosenheimer & Francis; Shantz, 1995), although this finding has been questioned.

Strang and Haughey (1998) place respite in the mind frame of the caregiver, prohibiting a program from claiming respite as a positive outcome unless it has been a positive experience for the caregiver. They conceptualize the caregiver's experience of respite as "a cognitive process of getting out of the world of caregiving and into their own world. In this world, they feel free from the responsibilities and worries of caregiving" (p. 231). It has been proposed that a caregiver's positive perception of respite is linked to the assurance that the client will benefit from the experience (Rosenheimer & Francis, 1992; Strang & Haughey; Theis et al., 1994).

As the literature indicates, the lack of a standard definition is problematic, pointing to deeper issues regarding the nature and purpose of respite programs. Issues such as *where* respite occurs pale in comparison to the discrepancies in *how* it occurs and whether it is defined by the program or by the experience of the family caregiver. Until these issues are addressed, an acceptable standard definition will not be possible.

Respite: Outcomes and Utilization

Respite outcomes. The respite literature falls into two distinct categories: studies that measure and describe outcomes and studies that evaluate utilization. The outcome literature suggests that positive outcomes for the caregiver are minimal at best. Some studies have found that while family caregivers described their reaction to respite in somewhat positive terms, their scores did not change significantly on measures of well-being (Lawton et al., 1989) or general health (Homer & Gilleard, 1994). Many of the eligible families did not use the services described in the study, resulting in the elimination of a large number of potential participants from the sample. Interestingly, Homer and Gilleard found that family members often visited the care recipient while he or she was in respite care. Reasons for visiting included missing the care recipient, feeling guilty, and wishing to ensure quality of care. In this group not all the care recipients had a diagnosis of dementia.

In a study by Larkin and Hopcroft (1993), caregivers reported a significant reduction in their psychological distress as measured using the Global Severity Index (GSI) while their kin was in a respite program, but this reduction was not sustained. Richey and Hodges (1992), in a case analysis of a woman caring for her elderly mother with dementia, also identified positive outcomes of respite. The daughter increased her time away from home, enjoyed the respite, and had a significant score change on the Child's Attitude Toward Mother scale when respite care was in place.

A grounded theory study by Worcester and Hedrick (1997) described the dilemmas of respite care and found that family caregivers characterized their relationship with formal care providers as "imposing." "Imposing" situations were those in which the family caregiver asked the formal care provider for special consideration, as well as when the formal care provider was demanding, made unwanted suggestions, or interfered with the caregiver's routines and approaches. The theory described the conservation of energy and resources as the central concern of the caregivers, and found that respite depleted rather than conserved energy and resources. In contrast, the evaluation of a descriptive program found that caregivers took the time to rest, socialize, or tend to their own health needs, while the clients benefited from the socialization with other people, the new surroundings, and the stimulation that family caregivers were not always able to provide (Rosenheimer & Francis, 1992). These studies also demonstrate the lack

of an acceptable standard conceptualization of respite to guide program development and evaluation — it is not clear that the respite programs actually failed, but it *is* clear that there is no well-supported way of evaluating them.

Resource utilization. Some of the resource utilization literature addresses the question of why family caregivers do or do not use formal supports such as respite. It also explores the under-utilization phenomenon more generally. King, Collins, and Liken (1995) found that families "owned" their difficulties, protected vulnerable members, and were self-reliant units, and that family boundaries governed help-seeking. A different perspective is reported by Adler, Kuskowski, and Mortimer (1995), who found that caregiver attitudes did not predict respite use. Strang and Haughey (1998) identify the factors influencing the caregiver's experience of respite as: the nature of the relationship prior to the onset of illness, the caregiver's role expectations, the type and quality of the respite service, and length of time in the caregiving role. Strang and Haughey's findings support Rudin's (1994) finding that the caregiver's view of the program and its effect on the kin influences attitudes towards respite care and the use of respite services. O'Connor (1999) also identifies role expectations as a factor influencing under-utilization of services. She suggests that giving up the caregiving role and accepting assistance could jeopardize the caregiver's sense of identity, even when the assistance is needed. Both O'Connor and Smyer (1999) call for research that addresses the meaning of service utilization to the caregiver.

Kosloski and Montgomery (1995) bring together the topics of outcomes and utilization. They point out that not knowing why family caregivers avoid or refuse respite precludes full program implementation, and that this circumstance has a built-in bias against results that demonstrate positive outcomes. They also note that, "perhaps most importantly, researchers and policy makers have yet to identify exactly what outcomes are appropriate for respite evaluations" (p. 73).

Thus the difficulties identified in the literature include inconsistencies not only in definitions but in the very conceptualization of what respite is and for whom it is intended. The fact that there are very different approaches to respite evaluation is therefore not surprising. The magnitude of these differences in definition, intention, and evaluation suggests that it is time to revisit respite, and to pursue in-depth explorations of the experience.

Design and Method

One western Canadian agency responded to the need for respite services by extending its Adult Day Program (ADP) to include weekend care as a pilot project. The expanded operation served to increase the options for family caregivers. While people with AD or related dementia participated in a therapeutic program, family caregivers had ready access to weekend relief.

The ADP operates as an eight-bed overnight respite service from Friday afternoon to Monday morning. The physical environment is fashioned to mirror the client's home. The bedrooms are large single rooms with matching comforters, drapery, and borders and a private bathroom. Family caregivers completed a care booklet containing information on the habits and preferences of the person with dementia. The program is designed to give clients the freedom to maintain personal schedules and routines; for example, one woman "slept in" on the weekend. The daily plan is relaxed and staff members encourage activity according to client preference; for example, many program participants enjoy walking, and that is always arranged when weather permits.

A qualitative evaluation was undertaken to explore the family caregivers' experience with respite. While the total evaluation included input from staff (focus group) and clients (interview and participant observation), only the family caregivers' evaluation is presented here. The agency initiated and was responsible for ethical review. Caregivers were informed that they were free to refrain from talking with the researchers and that failure to participate would not jeopardize the care of their family member. An advisory board composed of three current users of the program helped focus and guide the development of the evaluation. The advisory board stressed the need for a personalized approach and spoke strongly against the use of instruments because of the general fatigue associated with filling out forms and, more importantly, because they did not think questionnaires could capture their unique experiences.

The most suitable approach to the family caregiver data was goal-free evaluation. Patton (1990) supports this technique because it "opens up the option of gathering data directly on program effects and effectiveness without being constrained by a narrow focus on stated goals" (p. 117). He further explains that "goal free evaluation, in its search for *actual* effects, is an inductive and holistic strategy aimed at countering the logical deductive limitations inherent in the usual quantitative goal

based approach to evaluation" (p. 116). Patton's approach was particularly important for this project because, as discussed above, respite evaluations were not demonstrating significant effects using the traditional measures of stress, burden, well-being, and general health. In addition, as we have seen, appropriate outcome measures have not been established.

The data reported here were collected through telephone interviews that were tape-recorded and transcribed verbatim. The researchers asked specific demographic questions and obtained general information such as frequency of use. However, most questions were open-ended ones inviting the caregivers to talk about their experiences. They included: "How did you spend the time while _____ was attending the program?" and "How do you think _____ experienced the program?" Since the literature indicates that the caregiver's view is part of the respite experience, we considered it important to ask the latter question. However, the caregiver's response was not used in determining the actual experience of his or her family member.

Sample

A total of 25 family caregivers used the service over a 6-month period, and efforts were made to include the entire cohort of program users. The data reported are from 19 caregivers. Six caregivers were not included in the evaluation: five did not respond to repeated phone calls and one was not contacted because of the recent death of the family member with AD. The caregiver sample represents the major family roles of husband, wife, daughter, and son, as well as one sibling and one granddaughter (see Table 1). Of the 19 family caregivers, eight used the program between three and 12 times (see Table 2).

Analysis of Qualitative Data

The authors reviewed the data to identify themes and ideas. The latent form of content analysis directed the researchers to explore the meaning of the text through the words of the participants, rather than by setting and naming the categories before carrying out the analysis. The process resembles constant comparative analysis in that the researchers constantly move back and forth between the text and the emerging codes (Catanzaro, 1988). The units coded included words, phrases, or whole sentences that captured or reflected a single idea. The codes were brought together when they formed identifiable themes (Miles & Huberman, 1994). The transcripts were coded separately and then dis-

Table 1 *Relationship of Caregiver to Person with AD and Caregiver Age*

Relationship	Number	Age (years)
Husband	2	73, 80
Wife	8	71, 71, 63*
Daughter	3	49**
Son	3	33, 52***
Granddaughter	1	28
Sister	2	71, 65

n=19 * missing 5 ** missing 2 *** missing 1

Table 2 *Frequency of Program Use*

Caregivers	Number of Times Program Used
11	1
2	3
1	4
3	5
1	7
1	12

Note: Program used a total of 65 times

cussed until consensus was reached on the categories and themes. The manager and the director of the program reviewed the codes and themes before the final consolidation of the findings but suggested no changes.

Results

Based on the potential of eight beds per weekend for 24 weeks, 34% of the weekend respite beds were used (65 beds out of a potential 192) over the 6-month period. From the data obtained concerning utilization during this time, the researchers identified that the program enabled the family caregivers to achieve respite and derive satisfaction from it. Three categories were identified from the data analysis, two of which contained subcategories or themes that enriched our understanding of the caregivers' view and experience of respite. The three categories were: caregiver self-care, relief for the caregiver, and safety and comfort of the family member.

Caregiver Self-Care

The category of caregiver self-care identified the strategies used by the caregiver to promote his or her physical, social, and emotional well-being. Three themes appeared frequently: maintaining family and social relationships, maintaining own health, and catching up on sleep and rest. In essence, these themes demonstrated the caregiver's proactive use of the time gained by participating in the program.

It is clear from the interviews that caregivers used the respite service as a means of fulfilling their own needs. Yet the caregivers also expressed concern about the well-being of their family member with dementia. Many commented on positive aspects of the program such as the social and physical stimulation of their family member.

Maintaining family and social relationships. Caregivers used the respite program to pursue pleasurable activities, to visit relatives who did not live nearby, and to see friends and make new friends. They found opportunities to seek out and engage meaningfully with family and friends. For one caregiving wife, travelling to be with family was clearly important:

> *I have a son that lives in [a nearby island] and I went to visit him and I am going to do it again when my granddaughter graduates. I want to go to her graduation, you know, he [husband with AD] won't enjoy it.*

The comments of another wife highlighted the importance of engaging in activities and building friendships outside the caregiving experience:

> *Well, the thing is that I belong to the bluegrass society and folk song society . . . at the end of June they have three days of music at camp . . . a friend of mine — she's 76 — and I go . . . At the end of September there's a bluegrass festival. I'm going in a tent and the whole works . . . That's the thing that I do. I love music. That's how I make my friends.*

An interview with a caregiving granddaughter illustrated the impact of caregiving on all members of the family and the need for weekend respite:

> *I spend more time with the kids . . . You see, we all basically live our lives around her schedule . . . [During the week] between the three [kids] and Grandma it is who can yell the loudest to get the attention — so [the respite program is] a big help.*

Maintaining own health. Some caregivers needed time to deal with their own health issues. A caregiving spouse described the service as a "godsend" because she was able to admit her husband for weekend

care when she was ill. Others also described weekend care as an "emergency" service — during flu season, for example.

Several caregivers used the time to deal with their own psychosocial health needs, by relaxing, spending time outdoors, or being by themselves or with their partner.

One woman said, "I didn't go away, and I found that it was more beneficial just having the weekend, rather than going away and it being hectic and then coming home and being tired." Another woman indicated that respite gave her time to be alone with her spouse: "We get to go out for meals and do some other activities and things."

Catching up on sleep and rest. There was an overlap between maintaining health and getting sleep and rest. However, the caregivers focused particular attention on the area of sleep and rest, as captured in the following statements: "We have a monitor at night. We're often up two or three times a night, so putting her in respite allowed us to have a good night's sleep." "I slept . . . I was exhausted."

Relief for the Caregiver

Relief for the caregiver was very much the core of the respite experience but was difficult to capture. For example, participants did not clearly distinguish between stress and worry but were certain of which term they wanted to use. Here, relief is defined as the temporary alleviation of distress (stress and worry) or the responsibility of caregiving. The caregivers spoke of having a period of time when they could be free from stress and worry. One caregiver said, "This way actually it helps us a bit with the stress . . . you feel you can let go for a little bit and somebody else has the responsibility." Another reported:

> *I think it's a wonderful service. It gives me a break, because I worry about him all the time. It gives me a chance to get out with friends and know that he's properly taken care of. I know that they are very good to him there. . . he feels more at home there.*

Another caregiver said, "It's some place where I can leave her and not have to worry, and that's a big thing." The caregivers' ability to actually feel relief appeared to be tied to the knowledge that their kin was safe and well. The following section describes this relationship.

Safety and Comfort of the Family Member

The category of safety and comfort is defined as the caregiver's evaluation of the program in both process and outcome. The process criteria

that caregivers identified were opportunities for socialization, meaningful interaction, and sensory stimulation. One caregiver described the opportunities for socializing as: "She also gets to meet . . . and talk with different people; she's pretty well stuck in the house here." Caregivers identified the need for the person with AD to have the "right amount" of stimulation: "He needed the stimulation, which I couldn't provide for him, of other people and programs, and this [the respite program] was very good." Some caregivers identified specific activities that were important to their family member, such as field trips to local gardens and going for walks near the centre.

On the other hand, one family caregiver voiced a concern that socialization within the program might be less than optimal:

> *. . . the first time he came to [the respite program] I think he felt that there weren't as many people around as he wishes to have, not that he has them at home but he goes to [a different centre], you see, and he's been to those other places and there's always lots of people around.*

The family caregivers used the criteria of emotional state and physical appearance to evaluate the client's safety and comfort levels. They apparently assessed their kin both when they left for the centre and when they returned home. Some commented on the emotional state of the client: "He always comes away quite happy and looks like he had a really good time." "He seems quite tickled there, and it gives him a break away from home, because he gets kind of bored being always at home, and getting a break away actually does him good, because he's happy to get back home."

Family members also reported on the client's view of the experience: "My wife has remarked several times since then how good it was . . . how much she enjoyed it." "My wife frequently recalls people by name, people who were so nice to her, and how good they were. She raves about [the respite program]." "He thought [the staff] were great. He thought the food was good too." This data supports the idea of a relationship between the caregiver's ability to experience relief and the caregiver's perception that his or her relative is comfortable and safe.

Caregivers differed in their perceptions of the cost benefit ratio of respite care. All agreed on the difficulty of getting the client packed up, transported, and settled at the facility, with the client sometimes feeling angry or crying. However, some caregivers, particularly the multiple-program users, perceived the benefit to themselves and the physical and emotional benefit to their family member with AD as warranting all the trouble.

Discussion

The difficulties that arise in trying to capture the feelings and meaning of relief associated with respite are complex. This may account for the lack of positive outcomes identified in much of the respite research. We believe that some of the traditional quantitative approaches to respite, which are intended to decrease stress and burden, may be inappropriate. Our findings suggest that caregivers cannot feel and experience respite until they are assured of their kin's safety: there is a link between the caregiver's ability to experience respite and the assurance that the client will also benefit from it. These findings support those of Strang and Haughey (1998), in whose study caregivers described the attributes of respite that facilitate the experience of relief. Likewise, Rudin (1994) and Theis et al. (1994) found that caregivers judge the usefulness of a program on the benefits that both they and their kin derive from it.

Clearly, the need to attend to their own basic human needs was important to the caregivers in this and other studies. Larkin and Hopcroft (1993), in investigating caregiver stress before, during, and following respite, found that caregivers described improvements in sleep functioning and health, both of which they considered major benefits. Equally clear is the need to maintain family and social ties and avoid the social isolation described in the literature (Guberman, 1999). The flexibility of the weekend respite program optimized the caregivers' ability to participate in social and family activities. While these informal networks are the most effective means of achieving affective support (Bergman-Evans, 1994; Cohen, Teresi, & Blum, 1994; Theis et al., 1994), accessing them is difficult when respite care is limited (Richey & Hodges, 1992).

Our findings also support those of researchers who identify the temporary relief that accompanies respite. The caregivers interviewed for the present study described the lowering of stress as a short-term effect of respite. Although the relief was temporary, some of the family caregivers elected to use the program repeatedly. Other researchers echo the finding that the effects of respite are temporary (Adler et al., 1995; Larkin & Hopcroft, 1993).

Though this study contributes to our understanding of the respite experience for caregivers of kin with dementia, it is not without limitations. Most obvious is the fact that the findings are not generalizable. We do not have data from people who were fully aware of the new program but decided not to use it, or from people who were drawing

on other respite options in the community. Though family members were told that no identifying information would be shared with the program staff, participants may have been reluctant to share all of their thoughts and feelings.

In summary, it seems clear that the more traditional approaches to respite care could be replaced by models such as that of Strang and Haughey (1998), in which the experience of the caregiver is the focus. One could also argue for a more family-centred model that encourages researchers to explore the caregiver's description of what happens to their kin, thereby accounting for both members of the caregiver-care recipient dyad. An approach that reflects the findings regarding the caregivers' need for security and quality of care for their family member could help maintain family identity and reduce the feeling of abandoning or "handing over" a loved one. We see this as the next item on the agenda for respite research in Canada.

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Fostering Partnerships Between Peers and Professionals

Miriam J. Stewart and Linda Reutter

La participation du public figure parmi les cinq principes sur lesquels reposent les soins primaires. Les partenariats entre professionnels et clients s'inscrivent à ce principe. Cet article décrit comment les professionnels et les pairs peuvent travailler conjointement pour intervenir dans le cadre de groupes de soutien. Les auteures présentent des exemples tirés de trois études de terrain portant sur les survivants d'infarctus du myocarde et leurs conjoints, sur les parents d'enfants atteints de maladies chroniques et sur les femmes aînées handicapées. Dans chacun des groupes de soutien, pairs et professionnels partageaient le leadership et œuvraient en partenariat. L'article décrit les points suivants : les caractéristiques, les rôles et la formation des pairs et des professionnels; la collecte de données portant sur les pairs, les professionnels et les participants; et les processus d'intervention pertinents. Pairs et professionnels collaboraient en tant que co-leaders et partenaires dans 21 groupes de soutien s'inscrivant dans trois études. Les participants ont dit avoir été satisfait du leadership exercé dans les groupes. De plus, les animateurs professionnels et les animateurs œuvrant en tant que pairs ont reconnu l'importance du rôle et de la perspective de l'autre.

One of the 5 principles of primary health care is public participation. Partnership between professionals and their clients is compatible with this principle. This article describes how professionals and peers can work together in support group interventions. Examples are cited from 3 intervention studies focused on myocardial infarction survivors and their spouses, parents of children with chronic conditions, and older women with disabilities. Each of the support groups entailed co-leadership by and partnerships between peers and professionals. The article describes the characteristics, roles, and training of peers and professionals; data collection involving peers, professionals, and participants; and pertinent intervention processes. Peers and professionals collaborated as co-leaders and partners in 21 support groups in the 3 studies. Participants expressed satisfaction with the leadership of the support groups. Moreover, professional facilitators and peer facilitators each acknowledged the important role and perspective of the other.

The evolving health needs and accompanying health-system constraints in Canada cannot be addressed by professional resources alone. Accordingly, primary health care, which reflects a philosophy of citizen involvement, is being espoused increasingly by professionals. Nurses,

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who constitute the largest category of health personnel, proclaim primary health care as the key to the achievement of health for all Canadians in the new millennium (Canadian Nurses Association, 1995). One of the five principles of primary health care, public participation, is compatible with consumer control, client participation, professional-client interactions, consumer perceptions, empowerment, self-care, mutual aid, and professional-lay partnerships. This paper focuses on professional-lay partnerships in mutual aid groups.

The past several years have seen a growth in the *consumer-control* movement and increased tension in professional-lay relationships. Client *participation* at both the individual and collective level can be promoted through such mechanisms as volunteers, self-help mutual aid groups, and self-care, as professional roles are not rigidly defined in these areas (Gottlieb & Peters, 1991; Mezzina, Mazzuia, Vidoni, & Impagnatiello, 1992). Kristjanson and Chalmers (1990) observed *nurse-client interactions* and found that they were either nurse-controlled or jointly controlled. Further study of nurse-client interactions may help to promote public participation and to elicit public perceptions about nursing care (Powell-Cope, 1994). There have been few studies of *consumer perceptions* of nursing services. In one study, elderly clients perceived benefits from nurses' encouragement, support, education, and advice (Laffrey, Renwanz-Boyle, Slagle, Guthmillar, & Carter, 1990). *Empowerment* implies that clients have the authority to influence decisions and interventions through participation, choice, support, and negotiation (Connelly, Kleinbeck, Schneider, & Cobb, 1993; Wallerstein, 1992).

Health-system reform documents, at both the national and provincial level, that emphasize empowerment of populations and public participation (Angus, Auer, Cloutier, & Albert, 1995; National Forum on Health, 1997; Rootman & Goodstadt, 1996) reinforce the important role of self-help and mutual aid. *Self-care* and *mutual aid* are key mechanisms for promoting health (Romeder, 1990), and mutual aid groups can enable self-care. Gottlieb and Peters (1991) found that approximately 420,000 Canadians, or 2% of the population, had participated in a self-help mutual aid group in the preceding year. Such groups allow consumers to participate actively in their own health care and in health policy issues (Lavoie & Stewart, 1995) and are a cost-effective complement to professional services (Katz, 1993).

The community-based support provided by self-help groups augments the more specialized care provided by health professionals

(Elliot, 1999; Eng & Smith, 1995; McFarlane & Fehir, 1994). People experiencing chronicity, caregiving, and aging may require support that is not available in their depleted or strained networks. Yet the formal health system does not consistently acknowledge or address such needs. Frequently, peer support may be needed to supplement professional support. The nursing literature stresses the importance of lay-professional partnerships for people in rural areas (Cagle, 1993), Hispanic people (Courtney, 1995), and families of people with mental illness (Peternell-Taylor & Hartley, 1993). Such partnership models have been proposed by nurses (Courtney, Ballard, Fauver, Gariota, & Holland, 1996; Stewart, 1990; Stewart, Banks, Crossman, & Poel, 1994). A distinct advantage, beyond shared control, is the pooling of experiential (first-hand) and professional knowledge (Borkman, 1990). The professional's traditional "expert" role in dealing directly with individual patients/clients differs greatly from the collegial consultant role (Riessman, 1990) called for in working with self-help and support groups. Moving from expert provider to equal partner requires role modification and preparation (Courtney et al.; Stewart, 1990). The requisite role changes, ideological and control issues, mechanisms to expand interactions, and barriers posed by different knowledge bases have all been delineated in discussions of partnership (Lavoie & Stewart, 1995).

Despite embryonic efforts at partnership, "we have yet to determine mechanisms on how to synergistically blend professionally delivered services with mutual aid activities in a way that capitalizes on and preserves the unique contributions of each sector, and makes the two sectors equally legitimate and accessible" (Gottlieb, 1995, p. 233). After studying the role of public health nurses in Alberta in enhancing client competence, Reutter and Ford (1997) concluded that future research should explore "the intricacies of developing partnerships between professionals and clients that embrace a sharing of professional and experiential knowledge" (p. 150).

This paper describes how peers and professionals can work in partnership in mutual aid interventions. It cites examples from three nationally funded intervention studies focused on myocardial infarction (MI) survivors and their spouses, parents of children with chronic conditions, and women over age 65 with disabilities. It describes the characteristics, roles, and training of peers and professionals; data collection involving peers, professionals, and participants; and pertinent intervention processes.

Three Intervention Studies

In our preliminary assessments of the support needs of persons with various chronic conditions and their family caregivers, health professionals were identified only infrequently as a source of support (Stewart, 2000). In one study, for example, mothers of chronically ill children encountered "conflicted support" involving critical or condescending behaviour, predominantly on the part of health professionals. Indeed, the traditional relationship between health professionals and clients can be conflictual and disempowering (Borkman, 1990; Chesler, 1991). Because of the support deficiencies identified by people with chronic conditions and their family caregivers in these assessments, the participants expressed a wish for peer support. To illustrate, mothers of young children with cystic fibrosis wanted to have support groups consisting of other mothers of young children with cystic fibrosis, not mothers of children of any age with any chronic condition (Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994). Participants also expressed a preference for joint leadership of mutual aid/support groups by peers and professionals.

Consequently, we designed mutual aid/support groups for MI survivors and their spouses, parents of young children with chronic conditions, and elderly women with disabilities. Each of these support groups entailed co-leadership by and partnership with peers and professionals.

Cardiac Study

Despite the importance of spousal support for readjustment among MI survivors, there are no reports of interventions that test the efficacy of support from both professional *and* peer sources for *couples* coping with first-time MI. Accordingly, face-to-face support groups were designed to convey emotional, informational, and affirmational support specific to stressful situations encountered by MI survivors and their spouse/partner. These groups, which met weekly over a 12-week period, were led jointly by a couple coping with MI and a health professional. Group discussions were augmented by various techniques and resources depending on the topic (e.g., role playing, invited consultant or guest speaker, focused group discussions, guided group exercises). Twenty-eight people (14 couples) participated in five support groups in this demonstration project (Stewart, Davidson, Klassen, Makrides, & Wolf, 2000). All but one of the MI survivors were male. Survivors ranged in age from 42 to 71 years (mean = 57 years), while spouses ranged in age from 40 to 66 years (mean = 56 years). Half of the

participants reported incomes greater than $40,000/year; 40% had incomes under $30,000/year. Only 36% were employed; 64% were not employed or were retired. Almost all (96%) were Caucasian.

Parents' Study

Our earlier investigation of the support needs of mothers of children with a chronic condition revealed deficiencies in support from spouse/partner and professionals. Although mothers wanted support from their peers, they found it difficult to join face-to-face support groups because of caregiving demands and geographic isolation. Therefore, 12 telephone support groups, each co-facilitated by a parent and a health professional, were formed and met once weekly over a 12-week period. A total of 120 parents of young children with chronic conditions (cystic fibrosis, spina bifida, diabetes) participated in this randomized control trial (Ritchie et al., 2000). Most were mothers (n = 103). Of the 64 parents who participated in the telephone support groups (intervention condition), 54 were women. The mean age of the parents was 30 years; 84% had completed at least high school; 82% were married or living common-law. On average, the children of parents who participated in the support groups were aged 3 to 6 years and had one sibling; 36 children had spina bifida, 13 had cystic fibrosis, and 15 had diabetes.

Seniors' Study

As women's life expectancy is greater than men's, there are more elderly women than men living with some form of chronic disability such as stroke or arthritis. Given that these women frequently suffer losses from their natural network associated with aging and their social network is further limited by immobility, their support needs can be partly met by peers in mutual aid groups. In this study, women over age 65 with limited mobility (which prevented them from attending face-to-face support groups) met weekly over a 12-week period via teleconference. The telephone groups were co-led by a peer (i.e., an elderly woman with limited mobility) and a health professional. Twenty-six women with diverse disabilities (e.g., polio, spinal cord injury, osteoporosis, cardiovascular disease, arthritis) participated in four telephone support groups (Stewart et al., 2001). The mean age of participants was 75 years (range 66–93). Most women were widowed (61%) and most lived alone (78%). Participants were almost equally divided between urban and rural sites.

In all three of these support interventions, the peers and professionals were carefully selected and trained. Their characteristics, training, and roles are described below.

Characteristics of Peers and Professionals

In the *cardiac* support groups, peer leaders were couples (in which one spouse was at least 1 year post-MI) who demonstrated interpersonal skills, potential for leadership, and insight into requisite lifestyle adjustments. All peer leaders had extensive experience with community organizations (e.g., heart health). The health professional leaders (from nursing, social work, health education, and psychology backgrounds) had experience working with persons with cardiac illness and with community-based client groups.

The health professionals in the telephone support intervention for *parents* were nurses, occupational therapists, and physiotherapists. Although the intervention was open to couples, the peer leaders were all mothers.

One peer leader in the telephone support intervention for *elderly women* was 71 years of age and confined to a wheelchair because of polio. The other peer leader was 68 and legally blind. The professional leaders included a social worker and a physiotherapist whose practice focused on seniors, and a health educator with self-help group experience.

Training of Peers and Professionals

In these telephone and face-to-face support interventions, co-leadership was promoted by a joint orientation session for peers and professionals. Particular attention was paid to beliefs that might affect facilitators' ability to interact with participants, ways of using personal strengths to assist others, and strategies for building the abilities of group members. The training session addressed: (1) the purpose and intended outcomes of the support group; (2) the responsibilities of participants; (3) the nature, scope, and sequencing of topics for discussion; (4) strategies for handling group process issues, documenting support processes, and assisting individuals who required more support than the group could offer; (5) complementary roles of peer and professional facilitators; and (6) operational matters involving the use of technology (if relevant) and administrative details. Simulated situations and role play focused on group facilitation techniques. Feedback revealed that the training

session had anticipated issues that arose subsequently during the group sessions and had suggested appropriate strategies.

> *[The initial training was] very helpful…I learned a lot about what my role was as a facilitator in the group. It helped me feel confident about my ability to do this group.* [peer leader of parent group]

Check-in, or "booster," sessions for facilitators of the group interventions also proved successful. Every 4 weeks, peer and professional facilitators connected by phone with other facilitators, the trainer, and members of the research team to discuss progress, roles, and challenges. These sessions were viewed as helpful because of the exchange of feedback, guidance, and affirmation:

> *[The booster session] was really good. Quite a few issues came out and it was…supportive to hear about other groups. Good to have the reminder about group endings.* [professional leader of seniors' group]

> *That was a good session. It was interesting to talk to others about their experiences with their group.* [peer leader of seniors' group]

Resource manuals for facilitators were distributed and discussed during the training. For example, the facilitator manual for the *cardiac* support group outlined the responsibilities of the co-facilitators, the goals of the project, and themes for sessions. The initial session focused on the proposed topics and the expectations and commitments of group members. The outlines for the subsequent sessions focused on stressful situations for both MI survivor and spouse (e.g., hospitalization, health behaviours/lifestyle changes, health-care routines, recovery, caregiving roles, return to work, economic constraints, emotional impact of cardiac disease, intimacy, conflict, dependency), coping strategies, and support needed/available. Information on these topics was based on the literature and on feedback from a preliminary focus group of four couples who had coped with MI in the past. Case study scenarios, developed for each weekly theme, were distributed to participants. Similar resource manuals were developed for the peer and professional facilitators of the telephone support interventions for *parents* and *seniors*. To illustrate, weekly topics in the parents' groups were based on support needs pertaining to family routines and activities, child development, physical care, coordinating the child's health care, personal needs, roles other than caregiving, relationship with child with chronic condition, and relationship with spouse/partner. These support needs were expressed in the previous assessment study of mothers of children with a chronic condition.

Roles of Peers and Professionals

In the face-to-face *cardiac* support groups, information about the disease process, its treatment and management, and formal services was primarily the domain of the professional facilitator, whereas support related to coping strategies and informal help-seeking was the forte of the peer facilitator. Both facilitators addressed issues of family functioning and the relationship between the affected person and his/her spouse. In the telephone support groups, created for *parents* and for *seniors*, the professional facilitator contacted participants to determine a mutually agreeable time for the group meetings and worked with the telephone operator to initiate each teleconference session. Both professional and peer facilitators encouraged group members to voice their experiences and contacted individual group members between sessions regarding concerns or missed sessions.

In all three studies, the co-facilitators consulted participants during the initial session regarding specific foci of discussion and timing of sessions. Furthermore, they invited members to change topics in subsequent sessions. Hence there was shared decision-making pertaining to discussion themes.

Data Collection

In the three support group interventions, the professional and peer facilitators recorded field notes following each session, with particular attention to topics of discussion, coping strategies suggested, sources of support identified, support processes (i.e., social exchange, social learning, social comparison), and factors that might have influenced the discussion. The co-facilitators also recorded reasons for dropouts, their contact with members and members' contact with each other between sessions, and other intervening processes.

Peer and professional facilitators were interviewed jointly in some studies and individually in others about the training session; leadership issues; facilitators' roles, contributions, communication, and partnership; group processes; the advantages, disadvantages, and impact of the intervention; and interactions with group members following the intervention. Some of the interview questions were as follows:

> *During the session, what did the peer leader do that was different from the other group members and from the professional leader? Describe the frequency and focus of communications between the professional and peer group leaders. In your opinion, what were the advantages and disadvantages of having a peer leader? Was the professional leader a resource for*

the peer leader? If so, in what ways? Was there a partnership between the peer and professional leader? If so, please describe.

Following each session, participants made diary entries on the perceived importance of the topics discussed, their contribution to the discussion, group processes, leaders' roles, and co-leadership. Participants were also interviewed following the intervention about these intervention process issues and the perceived impact of the support groups.

The diaries, field notes, and post-intervention interviews yielded rich qualitative data on intervention processes such as participant input, roles of peers and professionals, and professional-peer partnerships. These intervention processes are reported here. (Standardized measures administered pretest, post-test, and delayed post-test generated quantitative data pertaining to outcomes in each study. These results are reported elsewhere.)

Data Analysis

For each of the three intervention studies, the qualitative data (participants' diaries, leaders' field notes, leaders' interviews, participants' interviews) were subjected to content analysis using a category system of key concepts and themes that were developed inductively from the data. The coding framework focused on content of the group discussion, group processes and other intervention processes, perceived impact of the intervention, and evaluation of the intervention. The derived categories met the following criteria: inclusive of the data provided, useful in describing participants' experiences and perceptions, mutually exclusive, and clear and specific. Reliability of selection of data elements for coding was achieved by setting the inter-rater reliability between coders at 80%. To assist with the management of the data, the computer-based software program Ethnograph was used. This paper describes common themes in the intervention processes across the three studies.

Intervention Processes: Common Themes

The facilitator field notes, participant diaries, and interviews of participants and facilitators revealed the following intervention processes: participant input, social comparison, social learning, social exchange, perceptions of peer-professional roles, and satisfaction with peer-professional partnership.

Participant Input

The success of the groups can be attributed in part to the fact that participants could control the content of discussions. One professional facilitator said:

> *I know I sort of relaxed after the first three or four sessions and...almost instinctively knew the next session is going to go okay... I relaxed and allowed the group to work the process themselves.*

In the *parents'* groups, for example, the choice of peer and professional facilitators, and the relationship between them, helped to set the tone and to create an atmosphere in which participants were encouraged to contribute. One mother reported: "Whatever we wanted to talk about was more or less what we discussed."

Some facilitators believed that the structure and facilitator guides were particularly useful during the early sessions:

> *It was good for us as facilitators, and also for them, to know that it was safe, at first, to have those topics to rely on. Now, near the end, they're more open and into their feelings.... But it was really good to have those topics at first, because people didn't know each other well enough to just say, "I've had an awful week. This is what's bothering me and can we talk about it?" Whereas if we were looking at physical care and looking at some specific kinds of things, they could contribute.*

Parents concurred that it was easier to select topics for discussion as group cohesion developed over time:

> *And the more we talked...each week everybody would open up a little bit more and talk.*

All facilitators of the *seniors'* support groups acknowledged the high level of member input in selection of topics. Sessions usually commenced with facilitators introducing potential topics, with members subsequently assuming responsibility for the direction of the discussion and identification of other topics. Facilitators reported that members preferred free-flowing conversation to structured discussion. The selection of topics was collaborative:

> *Leaders usually picked the topic. Usually it started that way, but something someone said would lead us off in other directions.* [senior]

> *Everyone has input...that was really nice about the group. Everyone felt part of the process. It wasn't a group run by two leaders. It was a collaborative effort.* [senior]

Three key processes were evident within these three support group intervention studies: social comparison, social learning, and social exchange.

Social Comparison

Social comparison is a process whereby people evaluate themselves and elicit information about their behaviour, abilities, and opinions through comparison with similar others. In the face-to-face support groups for couples dealing with a *cardiac* condition, all participants mentioned social comparison as a benefit. Similarity of life experiences played an important role in group development. In some groups, perceived lack of similarity with peers hindered comparison and depth of discussion. For example, some participants noted that they were younger than the other members of the group and had different circumstances, such as full-time jobs and young children. The tone of the group discussions was often set by the peer leaders describing situations similar to those experienced by members. Participants found solace in the realization that they were not the only ones facing these stressful situations.

Parents compared caregiving demands, ways of coping, age(s) of children, and severity of the child's condition. Dissimilar circumstances hindered the process of social comparison and the effectiveness of group interactions. As one mother said:

> *My daughter has spina bifida, but…she was more severe and had more problems than what the other children had. So I found it a little difficult there.*

Social Learning

Social learning involves a process of role modelling by peers and the fostering of self-efficacy. In the *cardiac* support groups, the process of social learning included receiving information based on both professional and experiential knowledge. Problems resulting from a lack of understanding about the cardiac condition were addressed through information exchanged among group members or offered by peer and professional facilitators. Participants also had the opportunity to gain insight into their reactions and behaviours through role modelling by other members. Furthermore, some participants learned about themselves by observing the behaviour of other members and peer leaders (vicarious learning). During post-intervention interviews, participants commented on the positive impact of informational support provided by the group on their knowledge, coping, and confidence.

In the telephone support groups for *parents* of children with chronic conditions, peer facilitators and other parents were the role models. One woman said she "looked up to" the other mothers and wanted to be more like them. Experiential knowledge was often solicited by the facilitators in the initial sessions and offered more spontaneously as the group developed.

> *Well, we bounced a lot of ideas off of one another. Like, "When I do this, this happens." You know, we did a lot of that... When you are doing that with others, you are learning. When situations arise, you remember, "Oh, I remember so and so said, or suggested..." And that stuff is in your mind and you think of it. It's got to help in the long run.*

Social Exchange

Social exchange refers to the give and take in groups through the sharing of ideas, information, and experiences. There was a strong sense of mutuality and equality among members of the support groups. In the three studies, most participants indicated that they both contributed to the group and benefited from it. Some peer facilitators reported that they learned from group members:

> *I feel I just gave and got support. That seems to be the way this group is. We listen to each other and then we offer up a [similar] situation or a potential solution.* [parent]

> *I think there was equality actually involved in everything.... We grew to respect each other's views, which is good.* [spouse of MI survivor]

Perceptions Among Participants of the Roles of Peers and Professionals

In the face-to-face support groups for couples dealing with *cardiac* conditions, scientific explanations (i.e., informational support) seemed to be received more favourably when delivered by a professional: "She explained everything" [survivor]. Peer facilitators provided information (on dealing with conflict, setting the mood for intimacy, relaxing, dieting, returning to work, etc.) in a user-friendly form and offered a realistic outlook on issues:

> *The support couple...was really able to explain things so very well, and give us [their] own experience on how [they] handled things and what was good. You really felt that [they] knew what [they] were talking about.* [survivor]

According to participants, peer facilitators offered positive feedback (i.e., affirmational support), reassurance, and hope that things would

ultimately return to normal. Peer and professional facilitators also demonstrated concern regarding the difficulties experienced by group members (i.e., emotional support). Participants believed that professional leaders set the tone, monitored the group process, and ensured that all members were heard, whereas peer leaders encouraged them to participate and provided reassurance and information on coping strategies.

In the telephone support groups for *parents*, the professional facilitator was perceived to be an "encyclopedia" who provided information and kept the discussion flowing and on topic. Many participants expected the professional facilitator to have current information related to their child's condition. The peer facilitator was viewed as the seasoned veteran who could provide information, having "been through it." The peer facilitators shared personal experiences and suggested strategies for coping with diverse issues, ranging from daily routines to life-and-death decisions. The participants contended that this experiential knowledge was valuable:

> *She was wonderful, and I did learn a lot from her. Her child was the oldest, with CF, and she knew just what to say. I know a couple of times I was having difficulties when we were talking about certain subjects. Like, we got talking about our fears one night, and my worst fear is losing her [daughter]... And when we were discussing that, she knew just what to say... as a parent and someone so associated with the disease, she really knew what I was thinking and feeling and she knew what to say to get me out of it.*

Satisfaction with Professional-Peer Partnership

In the telephone support group for *seniors*, participants believed that both peers and professionals offered unique support:

> *The peer [leader] could share her actual experiences with aging. She was one of us.*

> *[Professional] had a gift of making us speak, very comfortable. She made us all feel so special... [Peer] had a sympathetic understanding.*

Participants expressed satisfaction with the co-peer and professional leadership of the *cardiac* support groups. Moreover, the professional facilitators acknowledged the important role and perspective of the peer facilitators, as illustrated in the following quotations:

> *There was almost an instinctive identification from many of the people around the table to what the peer leaders experienced.*

> *I think that it's like anything in life, if you've had some experience with the problem, you bring a different perspective to it.*

The leadership fluctuated between the peer and professional facilitators. The joint interview of facilitators in the cardiac study revealed a consensus about the benefits of balanced leadership and egalitarian relationships.

> *I think we had similar values about how the process should go. It seemed to come out in those early weeks.... I don't think we had any clashes about how we felt we might support the process or intervene in any way with the process. I always felt very supported.* [peer facilitator]

> *The other thing that always challenges me as a [professional] facilitator is to...get out of the way of the process and to not control it too much.* [professional facilitator]

Parents also found the shared leadership of the telephone support groups effective. One parent said, "I think you need both. I mean, it's the theoretical and the applied. They go hand in hand." One benefit of co-facilitation was the different perspectives and experiences shared with the group. A mother observed, "They kept one another in balance. What one might have lacked, the other one made up for." A benefit noted by the facilitators was shared responsibility for the group. Furthermore, co-facilitation ensured continuity if one facilitator was absent, and it provided someone with whom to discuss concerns and to validate feelings following sessions:

> *I would always call my co-leader up immediately after the meeting and say, "How did you think that went?" We would post-mortem it for 10 minutes, which also helped very much.... I think that if I didn't have my co-leader's reaffirmation that we each share the same impression, it would have been extremely difficult to proceed.... I think there was a lot of self-support or mutual support.... It was excellent to have a co-leader.*

The peer and professional facilitators could rely upon each other in the initial stages of group formation and work together to maintain momentum when discussion slowed. One parent facilitator said, "It was less...imposing. The job was easier to take knowing there was someone else there for you."

Similarly, the shared leadership of the *seniors'* groups was viewed as effective and as creating a comfortable environment. As one elderly participant said:

> *[The shared leadership] was very effective. They knew more than we did and were very knowledgeable about the topics. They were both really good, interesting people. They were able to stimulate conversation*

without making people feel imposed upon. A good blend of practical experience and professional knowledge.

Discussion

Peers and professionals collaborated as partners in these 21 support groups. Participants reported that the partnership yielded affirmation, information, and emotional support. According to the qualitative data from interviews and the quantitative results of standardized measures, the need for support diminished and satisfaction with support increased following the interventions. Moreover, the interventions enhanced participants' competence and confidence, and diminished their feelings of loneliness. The National Forum on Health (1997) concluded that health-enhancing non-medical interventions can help to mobilize support at various levels of society (e.g., family, volunteer organizations, groups, communities). The group interventions reported in this paper mobilized supplementary support for people at risk for isolation, loneliness, and health-related problems. Participants, peers, and professionals were impressed by the positive contributions of partnership in these mutual aid interventions.

The collaboration between peers and professionals and the rapport underpinning their relationships contributed to the success of these support interventions. The guidelines for the preparation and practice of community health nursing in Canada (Canadian Public Health Association, 1990) clearly call for nurses to work collaboratively with self-help and support groups. In other studies, relationships between self-help groups and professionals that have been depicted as positive are those that are supportive, respectful, and helpful (Warner, 1992) and that involve shared leadership (Weiss, 1992). Partnerships that have been portrayed as effective by health professionals and members of self-help groups are those that are understanding, reciprocal, collaborative, egalitarian, and trusting (Banks, Crossman, Poel, & Stewart, 1997). Moreover, partnership necessitates role clarification, shared goals, risk-taking, flexibility, and an easing of professional control (Stewart, Banks, et al., 1994). In this context, a "coalition" or partnership between self-help groups and professionals can help to redefine professional-client relationships (Chesler, 1991) and roles.

In primary health care, the role of nurse changes from chief actor or expert provider to partner, and the role of client changes from passive recipient to partner (Courtney et al., 1996; Stewart, 1990). Nurses as professionals have a role to play in enabling consumers to empower themselves (Singer & Powers, 1992). The intervention studies reported in this

paper reflect the unique role that nurses can assume in both clinical and community settings — that of animator and facilitator of supportive social ties among populations in similar stressful circumstances (Gottlieb, in press a). Nurses can prolong the benefits of support groups by offering members the opportunity to transform themselves into a self-sustaining support group and by changing their professional role from that of facilitator to that of consultant and trouble-shooter (Gottlieb, in press b).

Barriers to collaboration between self-help organizations and health professionals lie in differences between professional and lay discourse (Simpson, 1996) and attitudes (Rogers & Pilgrim, 1997) and between professional and experiential knowledge (Borkman, 1990). Partnerships can feature tension between self-help/support groups and professionals (Wilson, 1993) as a result of differences in knowledge, roles, status, and power. In one study, professionals and self-help group members described relationships that were authoritarian, territorial, and competitive (Stewart, Banks, et al., 1994). Even relationships based on principles of partnership are not immune from power struggles (Banks et al., 1997). Whereas some professionals perceive self-help/support groups as a challenge to their professional authority and a threat to their power base and livelihood, other professionals willingly share power and control (Constantino & Nelson, 1995). Although support groups can develop problematic relationships with professionals resulting in "professionalization" and co-optation (Wilson), they can also enjoy empowering and positive relationships with professionals (Mitchell, 1996). Empowerment in health services requires a shift from hierarchical processes of control to horizontal processes of partnership (Townsend, 1994). Nursing practice can be informed by these three group interventions, which were characterized by shared power and control and in which professional and experiential knowledge were considered unique but complementary.

Despite positive attitudes towards the principles of primary health care, nurses report deficiencies in their knowledge, skills base, and education pertaining to social support groups and lay helpers (Stewart, 1989; Stewart, Banks, Crossman, & Poel, 1995). Nursing education should emphasize partnership roles (Hughes, 2000) and include training in consumer issues, mutual support principles (Simpson, 1996), and collaborative problem-solving. Intervention programs that foster collaboration should incorporate training and check-in sessions for peer and professional co-facilitators.

The nursing literature emphasizes the importance of partnerships in conducting research (Clarke, 1997; Dickson, 2000), and the principles of participatory research call for an equal partnership between researchers and participants. Nurses should document the flow of leadership between peers and professionals, and the unique and shared roles of peers and professionals in support groups and support dyads for different life stages and different stressful situations. While there has been some research on nurse-client interactions at the individual and family level, there is a lack of research exploring partnerships at the community level (Chambers et al., 1994). Moreover, the mechanisms for effectively blending professional and mutual aid activities should be examined in the context of future intervention studies (Gottlieb, 1995; Reutter & Ford, 1997). Clearly, peers and professionals can be effective partners in programs and in research.

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Book Review

***Cost-Effectiveness Analysis: Methods and Applications*, 2nd Edition**
Henry M. Levin and Patrick J. McEwan
Thousand Oaks, CA: Sage Publications, 2001, 308 pp.
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Reviewed by Gordon Cleveland

Individual decision-making is difficult enough; collective decision-making is an order of magnitude more complex and controversial. Consider some typical decisions that face us collectively as a society. What is the best course of treatment for AIDS? How much of our scarce health-care dollars for all ailments should be allocated to medical treatment, to prevention programs, to research? For children in primary school, is it better to reduce class sizes, to hire teaching assistants to work with teachers, or to increase special education resources?

Issues like these are controversial partly because the effects of different treatments are not well known, partly because the relative costs of different courses of action are not well known, partly because individuals have special interests and diverse biases which tilt them towards different alternatives. Cost-effectiveness analysis, and its cousins — cost-benefit analysis, cost-utility analysis, and cost analysis (all of which are discussed in this book) — attempt to make the process of collective decision-making more rational, less political, and more transparent.

Cost-Effectiveness Analysis: Methods and Applications by Henry Levin and Patrick McEwan is the second edition of a book that has gone through 17 printings since its origins in 1983. It clearly fills an important niche, and this edition has lots of improvements that will ensure its continuing popularity. In particular, there has been a substantial increase and improvement in the real-world examples used, and fuller discussion of cost-benefit, cost-utility, and cost analysis, each of which now gets chapter-length treatment. The book is designed to be introductory rather than comprehensive, and it is directed towards an audience interested in the analysis of issues in education. As the authors write: "The purpose of this volume is to provide a diverse audience — evaluators, educational administrators, and graduate students — with a systematic introduction to the use of cost analysis in educational evaluation" (p. 3). Virtually all of the specific examples used to illustrate the

use of cost-effectiveness analysis are from the educational field. Readers of the *Canadian Journal of Nursing Research* who are primarily interested in health-care issues might also wish to look at Drummond, O'Brien, Stoddart, and Torrance (1997) or Johannesson (1996), to which the authors refer.

Cost-effectiveness analysis is a technique for evaluating which of several alternative policies or treatments should be adopted to solve a collective problem we face as a society. The technique emphasizes both the measurement of benefits (i.e., "effectiveness") and the measurement of the costs of the treatment. As such, it is especially valuable for those charged with doing evaluation research, which, sadly, is often conducted with little regard for the full costs of alternative courses of action. Typically, cost-effectiveness analysis will assess both the effects and the costs of several possible solutions to a problem and will rank them in order of the dollar cost per unit of desired effect. Policy-makers will presumably be attracted to the solution that delivers the most "bang for the buck" — that is, the one with the lowest costs per unit of effect.

An example, provided by the authors, may be helpful. Four alternatives have frequently been put forward as possible educational reforms: a longer school day, computer-assisted instruction, cross-age tutoring in schools, and reduced class sizes. After the best available version of each of these reforms has been identified quite precisely, the costs and effectiveness of each are judged. Effectiveness is measured using a standard reading test and mathematics test. The costs of all the resources used in each intervention are tallied and effects on test scores are measured. This produces a CE (cost-effectiveness) ratio for each of the four possible interventions; the CE ratio is the number of dollars it would take to raise the average student's test scores in (a) reading, and (b) mathematics by one unit (one standard deviation). On both reading and mathematics, peer tutoring is found to be the most effective per dollar spent, with other alternatives being ranked differently according to whether reading or mathematics is taken to be the correct measure of effectiveness.

As the authors note, cost-effectiveness analysis is not a universal tool, good for all situations. In fact, its limitations are rather stringent. Used in the wrong situation, it will deliver poor results. In order for it to be fully applicable, the following three conditions must be met. First, the "benefit" of the interventions must be unidimensional. There cannot be two or three combined benefits, with one intervention delivering more of one benefit and another alternative delivering more of another.

So, if a medical procedure produces both improved longevity and decreased pain, cost-effectiveness analysis is not really appropriate (it cannot weigh up the trade-off between these two benefits). Second, the "benefit" must be common across treatments (it cannot be improved longevity for one and decreased pain for another). Third, the decision to do *something* must already have been made (e.g., to adopt one of the treatments that are currently being assessed). In other words, cost-effectiveness analysis cannot tell us whether it is worth spending public money improving AIDS treatments (i.e., whether the benefits of available treatments are greater than the costs); it can only rank alternative treatments to determine which of several alternative treatments delivers the best results per dollar spent.

When these conditions are not met, cost-benefit analysis should really be the preferred assessment method. Unfortunately, the authors are not very enamoured of cost-benefit analysis. Or, to be fair, perhaps they reflect the perceived feelings of their audience when they complain that cost-benefit analysis is really relevant only when the benefits can be easily measured in dollars (e.g., when things like improved incomes or decreased public social assistance payments are the main benefits of a policy being assessed). In truth, cost-benefit analysis can, when used creatively, cast a much broader net than this (see, for instance, the assessment of the costs and benefits of universal early-childhood education programs in Cleveland and Krashinsky, 1998).

Part of the problem is that cost-benefit analysis, especially the analysis of the benefit side, requires mastery of a fair number of technical details which are rooted in an understanding of microeconomic theory and its application to a particular situation. This is not an easy subject to present in only one chapter to an audience of non-economists. Levin and McEwan do a pretty good job, all considered, but it remains true that their discussion of cost-benefit analysis is fairly cursory. Further, their discussion of the measurement of benefits in the context of cost-effectiveness analysis is weaker than their discussion of costs. This is partly explained by the characteristics of their chosen audience. They explicitly direct themselves to educational evaluators who may have a pretty good general idea about benefits and how to measure them but have heretofore paid too little attention to costs.

For those looking for an introduction to cost-effectiveness analysis, and for those wishing to teach a course in evaluation research, this paperback text with its associated questions and exercises could be the ideal solution. It is marvellously clear and well-written and covers its chosen subject well.

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Submission deadline: July 15, 2001
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Submission deadline: October 15, 2001
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Submission deadline: April 15, 2003
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Submission deadline: July 15, 2003
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Health Resource Planning

March 2002 (vol. 33, no. 4)

Nursing shortages are once again making headlines in the mass media worldwide. Health resource planning attempts to determine the appropriate quantity, mix, and distribution of health personnel in order to meet the needs of the population. Historically, health resource planning approaches have been primarily single-discipline, intermittent, varying in quality, and supply-based in nature. They do not build upon the conceptual and analytic advances that have been made, and they rarely focus on outcomes. For this issue of *CJNR*, theoretical and research-based manuscripts on health resource planning that demonstrate innovative conceptual or analytic approaches with a focus on outcomes are requested.

Guest Editor: Dr. Linda O'Brien-Pallas
Submission Deadline: July 15, 2001

Coping/Adaptation

June 2002 (vol. 34, no. 1)

Coping and adaptation and their relationship to health remain key foci for nurses and others working in health care or doing health research. The field is ripe for advancement in our thinking. Facile linear models of conceptualization in this arena add little to our understanding or to the usefulness of the knowledge base for practice. We are calling for philosophical, theoretical, and research-based papers related to coping and adaptation in health and health-care situations. *CJNR* seeks manuscripts that focus on the theoretical or methodological debates, or that report research that tests innovative interventions with individuals, families, and/or caregivers to improve outcomes by enhancing coping resources or by altering the external social situations.

Guest Editor: Dr. Judith Ritchie
Submission Deadline: October 15, 2001

Please send manuscripts to:
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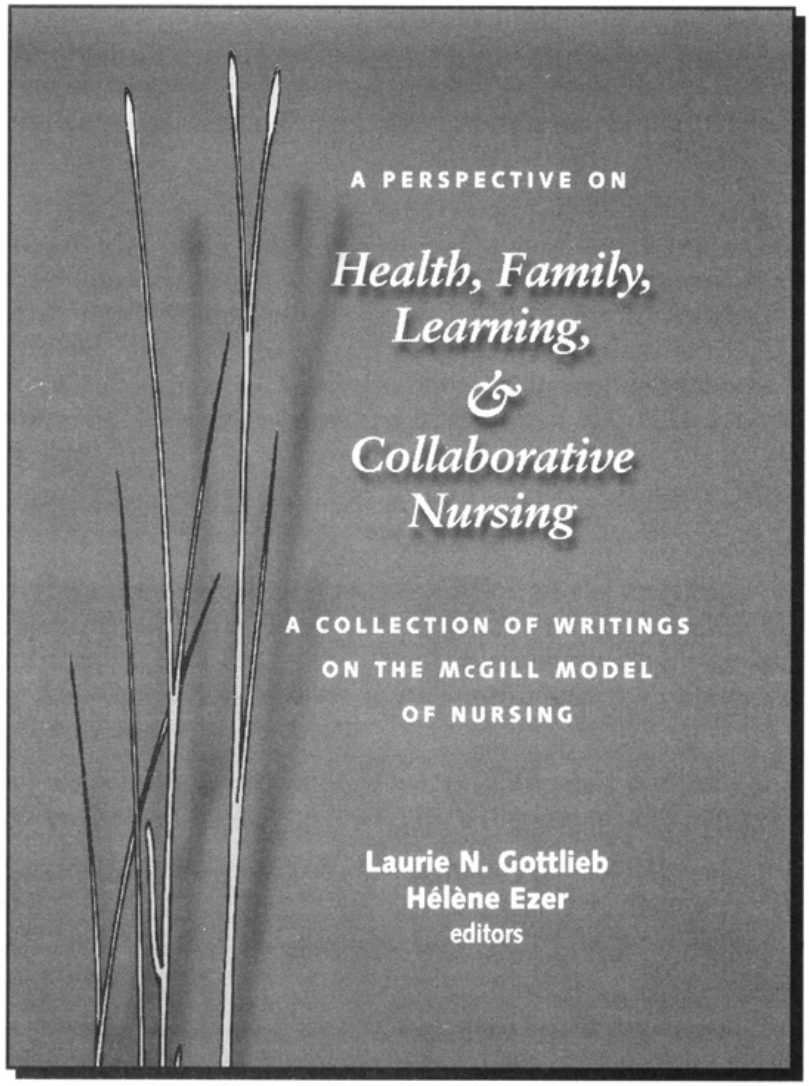

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Procedure: Three double-spaced typewritten copies of the manuscript on 8 ½" x 11" paper are required. Authors are requested not to put their name in the body of the text, which will be submitted for blind review. Only unpublished manuscripts are accepted. A written statement assigning copyright of the manuscript to the *Canadian Journal of Nursing Research* must accompany all submissions to the Journal. Manuscripts are sent to: The Editor, *Canadian Journal of Nursing Research*, School of Nursing, McGill University, 3506 University Street, Montreal, QC H3A 2A7. E-mail: jtoti@po-box.mcgill.ca

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

Title page: This should include author name(s), degrees, positions and affiliations, information on financial assistance, acknowledgements, and contact information.

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

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La *Revue canadienne de recherche en sciences infirmières* est publiée quatre fois par année. Son mandat est de diffuser la recherche en sciences infirmières qui a trait au développement des connaissances dans la discipline et à l'analyse de la mise en pratique de ces connaissances. La revue accepte également des articles de recherche liés à l'éducation, à l'histoire de même que des articles liés à la méthodologie, la théorie et l'analyse critique qui favorisent le développement des sciences infirmières. Nous vous invitons à nous faire parvenir également vos commentaires sur les articles publiés.

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

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