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GUEST EDITORIAL

## Home Care in Canada: Housing Matters

Patricia McKeever

It was a pleasure to work with Laurie Gottlieb to produce Volume 33 No. 2 of the *Canadian Journal of Nursing Research*. To the best of our knowledge, this is the first time a nursing journal has devoted an entire issue to home care. We hope that readers will share our pleasure in the result! The focus is very timely because, after more than a decade of dramatic "restructuring," most health care currently is provided in the homes of Canadians. The articles featured draw on an array of disciplines and perspectives, hence this collection contributes significantly to the growing body of knowledge pertaining to the reconfiguration of health-care systems that has occurred in many industrialized countries.

Although the contributors address very different issues associated with the provision of home care, each one highlights actual and/or potential inequities and tensions that have arisen. These inequities clearly revolve around axes of discrimination such as gender, disability, age, socio-economic status, ethnicity, and geographical location. Anderson poignantly asks us to grapple with the knowledge that increasing numbers of homeless Canadians are literally and metaphorically left "out in the cold" because they largely are excluded from home-care programs. By way of evaluating a telephone support intervention for family caregivers, Ploeg and her colleagues reveal that loneliness and isolation may characterize home-care experiences. These findings raise the possibility that under the rubric of community integration for citizens with disabilities, a paradoxical but unconscionable pattern of dispersed segregation has been created. Ward-Griffin describes the complex relationships and tensions that develop between nurses and family caregivers who provide care to frail elders, and Angus, by describing the particular predicaments women experience as they recover from heart surgery in their homes, illustrates how meanings of home are deeply gendered. Coyte and McKeever review home-care service utilization and financing in various provinces and conclude that national standards should be developed to increase the likelihood

that health-care systems will be equitable at micro, meso, and macro levels. Finally, Dyck implores us to recognize that because homes are unique places, they are highly relevant to the provision and receipt of home care and are worthy of study in their own right.

The devolution of health care to the home setting is changing the meanings, material conditions, spatio-temporal orderings, and social relations of both domestic life and health-care work. Unlike institutional settings such as hospitals, homes are idiosyncratic places with aesthetic, physical, and moral dimensions that reflect their occupants' gendered, socio-economic, and ethnic characteristics. Little is known about the suitability of contemporary homes for providing and receiving extraordinary care, or about the effects of superimposing one major institutional order (health care) over another (the family) in light of the changes in structure and function that both have undergone in recent decades. Furthermore, delivering home-care services is particularly challenging in Canada, because the population is ethnically diverse and unevenly distributed, climatic and geographical variations are extreme, and regional disparities in natural and sociocultural resources are marked. Finally, in a climate of political fiscal constraint, some publicly funded services such as homemaking are being discontinued, having been categorized as medically unnecessary and/or inessential.

To facilitate the development of an equitable Canadian health-care system in which home care is pivotal, the terrain needs to be re-conceptualized, re-explored, and re-mapped. Nurse theorists, practitioners, and researchers are ideally positioned to lead these endeavours. A useful point of departure is the contention of human geographers that people and places are always mutually constituting and interdependent. By recognizing and exploiting the ambiguous nature of the term "home care," the claim can be made that it should refer equally and simultaneously to *care of homes* and *care in homes*. Given that every home is actually or potentially a caregiving site, it is essential that all Canadians are adequately and appropriately housed. It is equally essential that all care recipients and members of their households receive the services, supplies, resources, and amenities that allow them to enjoy full citizenship.

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## Discourse

### The Politics of Home Care: Where Is "Home"?

Joan M. Anderson

"Why the hell should I vote? What have politicians done for me." ...[Bryan]...has been living on the streets of Centretown for the past two years. During the day, the 54-year-old sits with his dog on the pavement at the corner of Bank and Slater streets looking for change from passers-by.

At night, he goes back to his home — a dark corner of pavement behind the old Ottawa Technical high school on Albert Street. His bed is a pile of tattered blankets tucked in between a cement wall covered with graffiti and a partly rusted metal railing. (Nicolle, 2000)

What might be the meaning of home care for Bryan? Bryan's situation is by no means unique. As the health-care reform movement has gained momentum, and as the drive towards home-care management has accelerated, homelessness and poverty have become realities in the lives of many. An October 1997 headline in the *Globe and Mail* read, "Shelters running out of space: Warning sounded as winter looms." That same year, it was estimated that about 5,350 people in Toronto slept in shelters each night, compared to about 3,970 the year before. And the newspaper article reported that it was not only single men who faced homelessness; shelters for women and children were also full (Matas & Philp, 1997).

The crisis of homelessness reflects, among other social issues, a rise in urban poverty. Lee (2000), "using data from the 1996 Census and Statistics Canada's Low Income Cut-offs to measure poverty," found that between 1990 and 1995, poor populations in metropolitan areas grew by 33.8%, far outstripping population growth (6.9%) for the same time period (p. xv). Moreover, "certain population groups were more likely than others to be poor. The average poverty rate among all city

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residents was 24.5 per cent" (p. xv). The poverty rate among urban Aboriginal populations was 55.6%, "followed by recent immigrants (52.1 per cent), visible minorities (37.6 per cent), and persons with disabilities (36.1 per cent)" (p. xv). In 1993, according to Health Canada's Women's Health Strategy (Government of Canada, 1999), 56% of "senior women living alone or with unrelated persons, had low incomes. This compared with 38% of unattached senior men.... The lives of women seniors are more likely to be marked by poverty as a result of interruptions or non-participation in the paid labour force, or of low wages and few benefits" (p. 14). Homelessness among elderly women is an increasingly common phenomenon, as affordable housing becomes less accessible.

How should we understand and interpret home care against this social landscape?

In promoting the concept of home care, several government commissions have constructed "home" as the preferred locus of care. The British Columbia Royal Commission on Health Care and Costs noted, for example:

A clear message received by the commission is that, whenever possible, care provided in the home or on an outpatient basis is preferable to institutionalization.

According to a recent Ontario study, informal caregiving by family, friends, neighbours and volunteers provides up to 90 percent of the assistance required by dependent people. The caregiver is usually female, usually the spouse or an adult daughter of the dependent person. Professional caregiving only supplements and supports this informal system.

There are many costs involved with keeping people in institutions, and from a quality of life as well as an economic perspective, we must encourage home and community care. (Government of British Columbia, 1991, p. C-154)

Although the need for practical and appropriate support to "informal caregivers" is recognized in the above report, the effect of the caregiving process on a woman's life (e.g., what it means in terms of her employment outside of the home, pension benefits, etc.) is left unquestioned. "Most people feel better and get better more quickly in familiar environments with the support of family members and friends close at hand," echoed a later report (Government of British Columbia, 1993, p. 14).

One might argue that these documents were produced in the early 1990s, prior to the sharp rise in poverty and homelessness. Yet the

assumptions and ideologies that underpin them continue to drive health-care restructuring and the home-care movement. While crafted to reflect the notion that home care is for the good of the individual, the documents have as their fundamental precepts a concern with government spending on health; home-care management as a gendered activity, and the expectation that women will take on the role of caregiver; and the ideology of one's individual responsibility for oneself. Furthermore, the home-care discourse is based on deep-seated assumptions about home and family, for example, that we all have homes with family and friends close at hand to provide a nurturing environment, and that resources are in place (bedding, laundry facilities, etc.) to make home-care a reality. In other words, the notion of home care is entrenched in a particular meaning of "home" and constructed from a particular social location: the privileged middle class. Most importantly, it represents an off-loading of responsibility from the state to the individual and "family," even in those instances where "home-care services" are supposedly provided. As I point out elsewhere, the home-care movement must be understood in the context of societal and health-care ideologies that stress individual and family responsibility (Anderson, 1990) and that are enmeshed in the notion that personal misfortunes (as well as personal successes) are *individually* produced. In addition, as Williams, Deber, Baranek, and Gildiner (2001) argue, in the process of shifting the locus of care from hospital to community, we are shifting care "outside of the 'rules' and universal entitlements to medicare" (p. 10).

### **Towards a Critical Discourse: From Neoliberalism to Postcolonialism**

If the voices of those who live on the margins and in poverty are to be heard in the discourse on home care, alternative ideologies will have to be brought to bear on the reframing of issues: theorizing must include the "polyvocality of multiple social locations" (Brewer, 1993, p. 13). This will mean challenging neoliberal ideologies, crafting health policies that reflect the multiple social and economic contexts of people's lives, and developing integrated health and social policy initiatives. I draw upon Green's (1996) definition of neoliberalism as "an ideology that advocates an economic arena free of government regulation or restriction...and certainly, free of government action via public ownership. It advocates a retreat from the welfare state's publicly funded commitments to equality and social justice. It views citizenship as consumption and economic production" (p. 112). Neoliberalism drives the push towards privatization and profitization of health care. As Williams et al. (2001) note, "because it is publicly funded and regulated, medicare is

portrayed by adherents of neo-liberal free market ideologies as a source of inefficiency, waste, and abuse in an era of increasingly competitive global markets" (pp. 7–8).

Alternative discourses would hold the ideology of neoliberalism up to question and help us to move forward with an agenda that upholds the principles of equity and social justice. Postcolonial perspectives (see, for example, Bhabha, 1994; Quayson, 2000) that are now being drawn on in nursing (see, for example, Anderson, 2000a, 2000b) might provide a valuable theoretical stance from which to critique neoliberal ideologies and provide direction on issues pertinent to health and social policy and health-care delivery. Quayson tells us that "a possible working definition for postcolonialism is that it involves a studied engagement with the experience of colonialism and its past and present effects, both at the local level of ex-colonial societies as well as at the level of more general global developments thought to be the after effects of empire" (p. 2). While some might interpret such a definition as irrelevant to the Canadian context, I argue otherwise. I take the position that Quayson's perspective provides the conceptual apparatus for a critical analysis of the root causes of structural inequalities, and allows us to see how these inequalities are being produced and maintained by historical and social relations in a global and transnational context, underpinned by the dominant ideology of neoliberalism. Through the lens of postcolonial scholarship, and, I might add, a postcolonial *feminist* scholarship, we can critically examine the class relations produced by neoliberal ideologies and the forces that sustain the feminization of poverty. Such an analysis provides insight into the factors that lead to poverty and homelessness, and is a prerequisite for the development of transformative knowledge to guide health and social policy and practice that will address social inequities. "By transformative I mean knowledge that is, first of all, undergirded by critical consciousness... and that unmasks unequal relations of power and issues of domination and subordination" (Anderson, 1998, p. 205).

As we — nurse practitioners, administrators, educators, and nurse scientists — examine directions in health care for the 21st century, we must reflect on the scope of our mandate, given the issues that confront us today. There is overwhelming evidence that health cannot be separated from the social context of people's lives. It is also recognized that health-care delivery at the local level is bound up with global issues and the economic ideology of neoliberalism. In other words, health and health care are not isolated issues but are embedded in a nexus of social, historical, political, and economic relations. Nurses have a social and ethical responsibility to recognize these factors. However, we must

not only recognize them, but actively address them in our research and practice. For example, homelessness and poverty among marginalized groups, and the factors that contribute to women's poverty, must be central to our research agenda. But doing the research is not enough. We must position ourselves collectively to use this research as a means of influencing policy decisions; we must also put the research into practice as we reconceptualize the management of health care and home care for the years ahead.

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# Home Care in Canada: Passing the Buck

Peter C. Coyte and Patricia McKeever

Cet article offre une vue d'ensemble de la demande exercée au Canada en soins à domicile, met en évidence les postulats en matière de politiques sur la santé qui ont donné lieu à la promotion des soins de santé à domicile, et évalue les rôles actuels des secteurs privé et public dans le financement de ces soins. Des variations interprovinciales importantes en matière de coûts par habitant pour des soins à domicile et les inégalités potentielles en ce qui a trait à l'accès à ces soins constituent des problématiques qui doivent être résolues par les gouvernements provinciaux. Un consensus doit être établi quant aux services médicalement et socialement nécessaires qui sont réglementés par des normes pancanadiennes, et ce peu importe le contexte dans lequel ces services sont sollicités, reçus et dispensés. L'élaboration et l'application de normes pancanadiennes relativement aux soins à domicile qui s'ajouteraient aux principes énoncés dans la Loi canadienne sur la santé constituerait une mesure pertinente permettant de s'assurer de la capacité du système de santé canadien à relever les défis de ce nouveau millénaire.

This paper provides an overview of Canadian home-care utilization, highlights the health-policy assumptions that have resulted in an increasing reliance on in-home services, and assesses the current roles of the private and public sectors in the financing of home care. Significant interprovincial variations in per capita home-care expenditures and potential inequalities in access to home care call for resolution by federal and provincial governments. There is a need for consensus with respect to medically and socially necessary services that are subject to national standards, irrespective of the setting in which services are sought, received, and delivered. The development and enforcement of national home-care standards that complement the principles of the Canada Health Act would be a useful first step in ensuring that the Canadian health-care system is ready to confront the challenges of the new millennium.

## Introduction

The funding, organization, and delivery of home-care services have become prominent health-policy issues in Canada. In the last 25 years, the growth of public home-care expenditures has outpaced that of other health expenditures, yet home care accounts for only 5% of total health

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spending. Many factors account for this growth in home-care spending, including expanded eligibility, increased accessibility, technological advances, system restructuring, and demographic changes. However, a key is the common belief that significant public-sector savings may be realized by redirecting care away from institutions and towards the community (Hollander, 1994; Jackson, 1994; Jacobs, Hall, Henderson, & Nichols, 1995).

Shifts in responsibility for caregiving and for the financing of home care are the focus of this paper. First, health-policy changes that have resulted in an increasing reliance on in-home services are highlighted, with calls for evidence to direct and support these changes. Second, current and projected home-care utilization patterns are discussed. Home-care expenditures and shifts in the financing of home-care services are reviewed. Finally, recommendations are made for more equitable access to these services.

### **Health-Policy Shifts: Assumptions and Gaps in Knowledge**

One of the major social changes of the last quarter century has been a shift in the setting for health-care delivery away from institutions. Policy development and system restructuring are continuing with very little evidence that what we are doing is right. Moreover, assumptions about the benefits of home and community care have taken on the status of conventional wisdom.

Restructuring has moved many types of health care, for people of all ages, into the home. It has shifted the emphasis from institutional care to home care, provided by an array of caregivers, including family and friends. The Canada Health Act (CHA), from its inception in 1984, has privileged care provided by physicians and all care and services provided in hospitals. However, in the last 16 years the share of total health expenditures covered under the principles of the CHA — that is, expenditures on hospitals and physicians — fell from 57% to 45.5% of total spending (Canadian Institute for Health Information, 1999). Thus, the CHA applies to the minority of health spending. While most provinces have chosen to publicly fund components of home care, shifts in the setting of care have opened the door for a major reallocation of health costs from the public to the private sphere, thereby eroding a hallmark of Canadian identity, the health-care system. Key policy issues that have arisen include: determining the base level of public coverage, the extent of cost-sharing (i.e., public with co-payment, private payment), and the role of the private sector in service delivery.

Policies advocating the provision of health and social services in the homes of Canadians have been supported with three commonly held assumptions. First, it is believed that people want to assume substantially greater responsibility for health-care delivered at home; want to be discharged from acute care early; want to remain in the community rather than reside in long-term-care facilities; and have family and friends willing and able to provide informal care. However, there is considerable concern about the potential responsibilities and costs that will be shouldered by family members and friends. Moreover, the advent of the "sandwich generation" — those responsible for both children and elderly parents — raises doubts about whether assumptions regarding the supply of informal care are appropriate for the new millennium (Keating, Fast, Frederick, Cranswick, & Perrier, 1999).

Second, it is assumed that Canadian housing and employment circumstances permit the safe shift of effective care to the home. Generally speaking, even the finest contemporary homes are not designed to facilitate the long-term provision of care and may be a sub-optimal environment both for clients and for in-home providers of informal and formal care. Complex and technically sophisticated care is being provided in the home now, but we do not know whether family members have the resources and amenities to cope safely with the changes. Moreover, while evidence demonstrates that women play the predominant caregiving roles, changes in patterns of labour-force participation and other competing demands on time raise questions about whether these supply conditions will persist.

The final commonly held assumption is that equal or better care at a lower cost will result from shifting care from institutions to the home. Although there are few empirical studies evaluating the costs and benefits of home supports, a report released by Saskatchewan's Health Services Utilization and Research Commission states that seniors receiving preventive home care were 50% *more* likely to lose their independence or die than those not receiving any services. In addition, average total costs for recipients of preventive home care were about *triple* the average health costs for non-recipients. In comparison, residents of seniors' housing were 63% *less* likely to lose their independence and 40% *less* likely to die than other Saskatchewan seniors. Residents of seniors' housing have about the same total health costs as non-residents (Health Services Utilization and Research Commission, 2000). Reviews of the international literature and reviews conducted for the Health Services Restructuring Commission of the province of Ontario (Coyte & Young, 1997b; Coyte, Young, & DeBoer, 1997; Health Services Restructuring Commission, 1997) found very little compelling evidence to support the

cost-saving assertions for home care (Health and Welfare Canada, 1990; Parr, 1996; Price Waterhouse, 1989), and few of the studies reviewed were directly applicable to Canada. Essentially, the research to date has been of limited quality (Parr) and has yielded diverse cost and outcome estimates (Hughes et al., 1997).

Thus, while home-care expenditures have risen, this increase has occurred without compelling evidence of cost-effectiveness (Health Canada, 1992; Parr, 1996; Price Waterhouse, 1989). Health managers, providers, and policy-makers have been frustrated by the lack of data concerning the costs and consequences of in-home services (Health and Welfare Canada, 1990; Jacobs et al., 1995; Parr; Price Waterhouse; Richardson, 1990). Little is known about the impact of home care on health and lifestyle, or the extent to which the burden of care has shifted from institutions to patients, families, and community agencies (Parr). Moreover, there is a growing perception that unless these services are targeted to specific client groups they will not represent a cost-effective alternative to institutional care (Weissert, 1985, 1991; Weissert & Cready, 1989; Weissert, Wan, Livieratos, & Pellegrino, 1980). Two recently heralded studies concerning the use of home care following acute hospitalizations (Saskatchewan Health Services Utilization and Research Commission, 1998) and as an alternative to facility-based long-term care (Hollander, 1999) suggest that home care may lower costs without adversely affecting the health of Canadians. While neither study used randomization to identify the unique contribution of home-care services, both suggest that cost savings might result from modifications to health-service delivery and organization. However, before any radical change to the health-care system is undertaken, evidence is needed to confirm these preliminary results.

In addition, while various organizational and financing reforms, such as the introduction of Community Care Access Centres in Ontario (Ministry of Health, 1996), have been designed to promote more equitable access to services and to lower costs through increased competition, their impact has yet to be determined. The home-care sector is labour-intensive; hence a lower cost entails lower wages and fewer benefits for nurses and other personnel, which may erode staff morale and adversely affect the quality of care. These observations have recently been echoed by the Registered Nurses Association of Ontario (1999), which highlighted the fact that competition results in the delegation of tasks to unregulated providers and reduces the number of in-home visits to care recipients. Clearly, more evaluation is required to identify the consequences of competition in order to inform health management and policy development.

### **Current and Projected Home-Care Utilization and Expenditures**

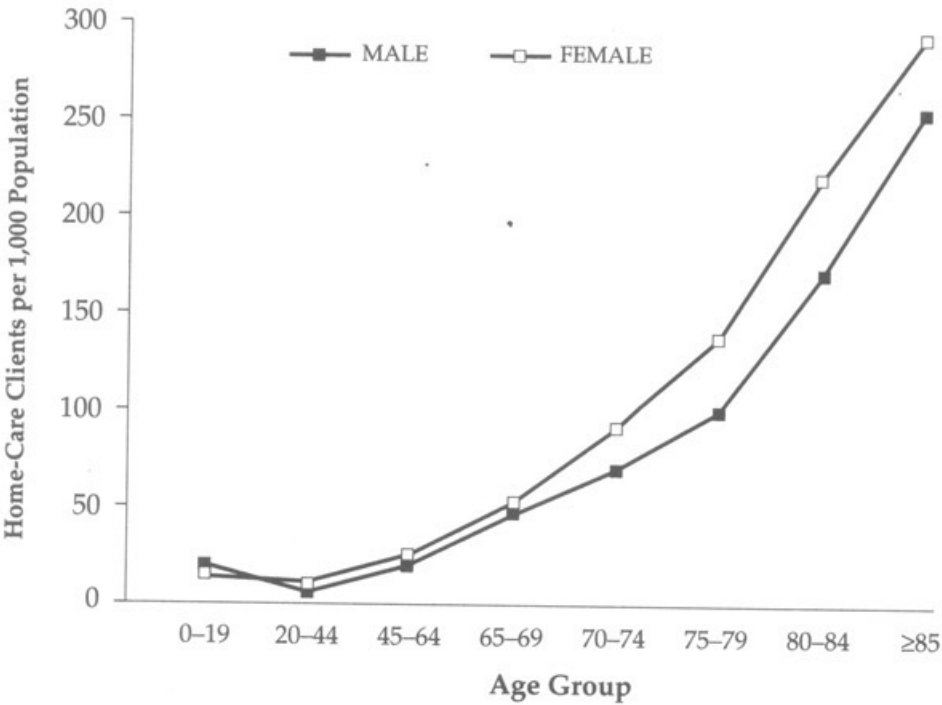
Currently, an array of home-care agencies and providers participate in the delivery of a complex range of health and social services to a variety of clients (Coyte & Young, 1997a; Health Canada, 1999; Stewart & Lund, 1990). The range of services includes nursing, social work, physiotherapy, audiology, occupational therapy, meal delivery, and personal support. While most clients receive these services to prevent or retard the deterioration of health and to help them to maintain their independence, others receive rehabilitation services following, or in lieu of, hospitalization. It is useful to characterize access to in-home services in terms of two dimensions: the propensity to use home care (i.e., population-based rates of utilization); and, once home care is assured, the intensity (or the number and range) of in-home services received.

Differential access to services has been associated with the gender, age, and regional location of the client. In Ontario in 1995, the most recent year for which client-specific data are available, 261,635 clients received at least one provincially funded home-care service. The majority (60.1%) of clients were women. Although close to 50% of men receiving services were under 65 years of age, only 35% of women were in that age group. Almost 20% of male clients were under 20 years of age, while fewer than 10% of female clients were in that age category. Figure 1 depicts rates of home-care utilization per 1,000 population by age and gender. While the number of clients under 65 years of age is small, their rate of utilization is low (under 2%) compared to persons over 65. Women have 20% higher rates of utilization than men. The fact that utilization rates increase with age and are higher for women could reflect the needs of the elderly and persons living alone, who may have limited access to informal care.

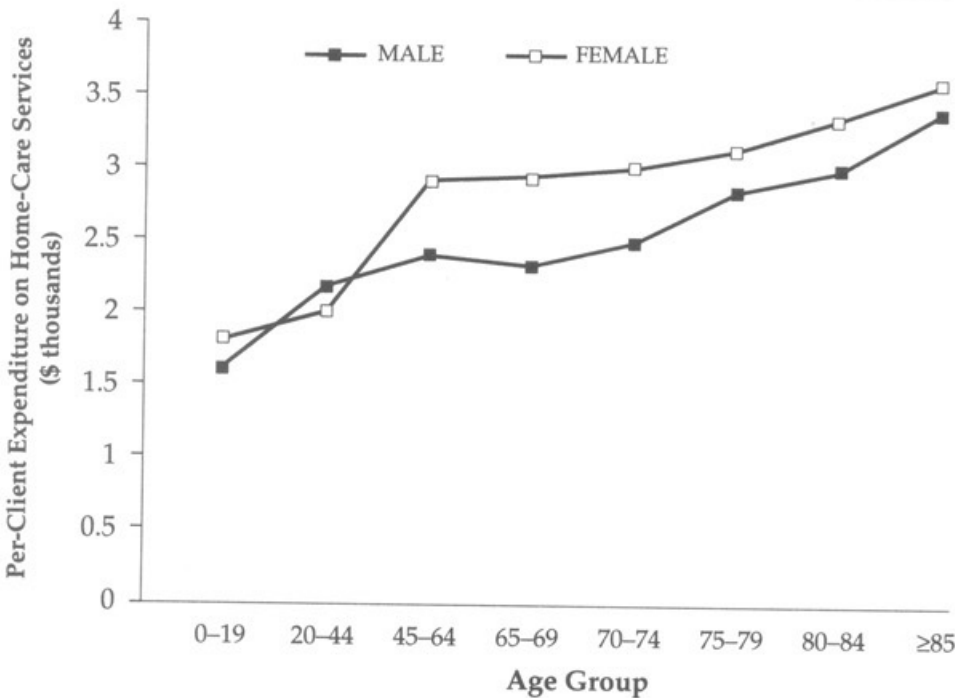
Figure 2 shows the intensity of home-care utilization by age and gender. While average annual provincial home-care expenditures per client are substantial, at \$2,736, total expenditures for clients under 20 years of age are approximately 60% of the provincial average. In contrast, the intensity of utilization by clients over 85 years is more than 20% greater than the provincial average. Hence, intensity of home-care use increases with age and is higher for women over 45 years.

Indications of intraprovincial variations in home-care utilization were first reported in Canada by Ontario's Health Services Restructuring Commission (Coyte & Young, 1997a; Coyte et al., 1997; Health Services Restructuring Commission, 1997) and later in three publications (Coyte & Axcell, 1998; Coyte & Young, 1999; Young, Coyte, Jaglal, DeBoer, & Naylor, 1999). These variations concerned the use of home-care services

**Figure 1** *Home-Care Utilization Rates by Age and Gender in Ontario, 1995*



**Figure 2** *Intensity of Home-Care Utilization by Age and Gender in Ontario, 1995*



following hospitalization. Irrespective of the methods used to measure variations, there were moderate to substantial regional variations even after adjusting for the composition of the population (Coyte & Axcell; Coyte & Young, 1997b, 1999; Coyte et al., 1997; Health Services Restructuring Commission; Young et al.). While the use of home-care services follows a similar pattern of variation as that reported for many health-care services (Coyte & Young, 1999; Coyte et al., 1997; Kenney, 1993), more information is required to track the extent of such variation in order to assess its determinants and to measure the resulting consequences for Canadians.

### *Home-Care Expenditures: Variations and Sources*

Between 1975 and 1992, the annual growth rate for home-care expenditures was almost double that for total health spending (19.9% vs. 10.8%). Since 1992, home-care expenditures have risen at threefold the rate for other health spending (9.0% vs. 2.2%). Despite such dramatic growth, less than 5% of national spending was directed to home care in 1997. Further, there are wide interprovincial variations in home-care expenditures. Although on average Canada devoted \$69 per capita to home care in 1997, spending in New Brunswick, Newfoundland, Ontario, and Manitoba was almost threefold that in Quebec and Prince Edward Island (see Table 1). These variations persist even after adjusting for the composition of the population.

**Table 1** *Interprovincial Public Home-Care Expenditures per Capita, 1997*

Newfoundland	\$92.25
Prince Edward Island	\$34.26
Nova Scotia	\$79.94
New Brunswick	\$94.52
Quebec	\$37.36
Ontario	\$91.08
Manitoba	\$90.50
Saskatchewan	\$68.71
Alberta	\$52.45
British Columbia	\$62.06
<b>Canada</b>	<b>\$69.20</b>

Source: Health Canada (1998).

At least five factors account for this wide interprovincial variation in home-care spending. First, there are variations in the level of total spending on health care, with per capita spending in Manitoba and Ontario almost 25% greater than that in Quebec (Canadian Institute for Health Information, 1999). Such variations affect the means available to allocate scarce provincial funds to all sectors of health care, including home care. Second, there are variations in the emphasis on the home as a setting for health and supportive care. In some provinces, community clinics and geriatric day centres are used more extensively than home care. Third, variations in the composition of the population, the availability of community supports, and social context influence the need for home care. Fourth, due to variations in the pace and extent of health-system restructuring, provinces are at different stages in the transition to home and community services. Finally, since home-care expenditures are defined as the sum of the number of services provided and the cost of each, some interprovincial variation may be attributable to each component of total spending.

If we distinguish between expenditures covered by the CHA, comprising hospitals and physician services, and those not covered, such as home care, it is clear that the share of private health financing has increased (see Table 2). While in 1975 the private sector accounted for 23.6% of total health spending, in 1999 it accounted for 30.4%. More than 80% of the growth in the private share is attributable to passive privatization, or cost shifting by government, the remainder being attributable to expanding markets and active privatization. Although there is a lack of robust information concerning the extent of private financing for home care, two surveys of household expenditures warrant consideration. A survey conducted by Price Waterhouse Coopers ("Home health care," 1999; PricewaterhouseCoopers Health Care Group, 1999) concluded, based on responses from over 2,000 Canadians, that 25% of home-care clients have average monthly out-of-pocket expenses of \$407, and an additional \$138 for prescription drugs. These expenditures represent almost 15% of average annual public home-care expenditures per client in Ontario. In addition, home-care clients recently discharged from hospital spent approximately \$200 per week privately securing home-care services and supplies. A survey conducted by the privately owned home-care provider We Care Health Services ("How would you pay for home care?," 1999) estimated, based on responses from 33 of its 58 offices across Canada, that home-care clients incurred 24.5% of the cost of their nursing services and 59.3% of the cost of other support services. Average weekly out-of-pocket expenditures were estimated to be \$283. While efforts may

**Table 2** *Public-Private Financing of Various Categories of Health Expenditure*

		CHA Expenditures	Non-CHA Expenditures	Total
Public	1975	\$7,009.3m (74.9%)	\$2,351.6m (25.1%)	\$9,360.9m
	1999	\$36,852.8m (61.6%)	\$22,983.4m (38.4%)	\$59,836.2m
	Growth rate p.a.	7.2%	10.0%	8.0%
Private	1975	\$344.9m (11.9%)	\$2,554.3m (88.1%)	\$2,899.2m
	1999	\$2,332.3m (8.9%)	\$23,844.6m (91.1%)	\$26,176.9m
	Growth rate p.a.	8.3%	9.8%	9.6%
Total	1975	\$7,354.2m (60.0%)	\$4,905.9m (40.0%)	\$12,260.1m
	1999	\$39,185.1m (45.6%)	\$46,828.0m (54.4%)	\$86,013.1m
	Growth rate p.a.	7.2%	9.9%	8.5%
Private share	1975	4.7%	52.1%	23.6%
	1999	6.0%	50.9%	30.4%
Note: CHA Expenditures refers to expenditures on hospitals and physicians. Non-CHA Expenditures refers to all others.				

Source: Canadian Institute for Health Information (1999).

be required to ensure the reliability of these estimates, the results highlight the extent of private home-care financing.

In order to more precisely determine the extent of private home-care costs, data provided by three national in-home service providers (Comcare Health Services, Victorian Order of Nurses for Canada, and We Care Health Services) were reviewed. While there was some variation in the revenue share among organizations, and more dramatic regional variation, about 80% of each organization's total revenue was derived from provincial or federal government sources. If this share was maintained across all home-care provider organizations, in 1997 private financing of home-care services exceeded \$500 million and total (public and private) home-care expenditures were approximately \$2,620 million.

Future demographic changes are expected to have a profound effect on home-care expenditures. Based on Statistics Canada (2000) projections regarding population growth and the age-gender composition of Canadian society, home-care expenditures are expected to increase by almost 80% between 1999 and 2026. The magnitude of the effect of these changes is enormous, with the home-care share of total health spending expected to reach double digits by the year 2026.

### *Equitable Access to Home-Care Services in Canada*

There are significant and potentially troubling variations in the funding, availability, accessibility, and quality of home care throughout Canada. These variations have sparked recommendations that the federal government revise and extend public insurance to ensure that all residents of Canada, irrespective of geographic location, have the benefit of equivalent levels of publicly insured home services. Such federal incursion into areas of provincial jurisdiction would require consensus on the entitlement, scope, and allocation of services. This would involve agreement on the terms and conditions of public insurance, such as the range of insured services (social/medical), the duration of coverage (acute/chronic), and the settings in which the services are provided. Of equal importance would be consensus on an array of financial concerns, including mechanisms to ensure equitable access, the scale of deductibles, the size of co-payments, the level and means by which service providers are reimbursed, and determinants of cost-effectiveness.

One way to achieve equitable access would be to identify and develop a "standard basket of goods," thus ensuring that all provinces and territories receive funding for the same range of in-home services. Ontario may be used as the standard for these calculations (Coyte, Hall, & Croxford, in press). This should not be taken to imply that the current level of home-care expenditures in Ontario and their allocation across alternative home-care providers are optimal.<sup>1</sup> However, the province is useful as a baseline for two reasons. First, data are available on patterns of home-care use and unit costs by age and gender in Ontario. Second, the province is in the upper range of per capita home-care expenditures. Hence, the data provide a baseline for comparison and an estimate of the increase in public home-care financing needed to ensure equitable access.

Table 3 illustrates actual and projected home-care expenditures in 1997 for all Canadian provinces and territories. The projections are based on three ingredients: the demographic composition of each region (Statistics Canada, 1998); the relative intensity of home-care expenditures by age and gender in Ontario; and per capita expenditure on insured in-home services in Ontario. The funding variance measures the (percentage) increase in expenditures needed to ensure that all Canadians have

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<sup>1</sup> The choice of Ontario would raise concerns if higher funding for home care were reflective of a policy decision to favour home care over hospital care. However, there is a paucity of evidence to support this contention: first, interprovincial per capita home-care spending is invariant to per capita hospital expenditures; and second, 1997 per capita hospital expenditures for Ontario (\$750) were not significantly different from those for Canada (\$766).

**Table 3** *Actual and Projected Public Home-Care Expenditures in Canada and in the Provinces and Territories, 1997*

	Actual (\$ millions)	Projected Population-Based Funding (\$ millions)	Funding Variance (%) $\frac{(\text{Projected} - \text{Actual}) \times 100}{\text{Actual}}$
Newfoundland	51.991	47.488	-8.7
Prince Edward Island	4.701	13.885	195.7
Nova Scotia	75.777	93.326	23.1
New Brunswick	72.026	73.202	1.6
Quebec	277.198	677.452	144.4
Ontario	1,038.929	1,038.929	0.0
Manitoba	103.640	117.587	13.5
Saskatchewan	70.327	112.150	59.4
Alberta	149.318	223.730	49.8
British Columbia	244.113	373.793	53.1
Yukon	1.427	1.452	1.8
Northwest Territories	6.528	2.707	-58.5
<b>Canada</b>	<b>2,095.975</b>	<b>2,775.551</b>	<b>32.4</b>

Source: Health Canada (1998).

levels of funding for insured in-home services equivalent to Ontario residents. A negative variance, such as that reported for Newfoundland, indicates that current levels of public funding are more than adequate to guarantee services equivalent to those available in Ontario. A positive variance indicates that current funding is lower than Ontario's.

Given the wide variation in home-care funding in Canada, it is not surprising to find substantial shortfalls. Funding in both Prince Edward Island and Quebec is less than 50% of that required to ensure equivalence with Ontario. Even in Alberta, British Columbia, and Saskatchewan, funding would need to be increased by approximately 50% to match Ontario levels.

The estimates provided in Table 3 suggest that an increase in home-care funding of almost \$700 million is required to ensure that all residents of Canada have insured home services equivalent to those currently

available in Ontario. While this is an increase of more than 30% in public home-care expenditures, it represents an increase of only 1.3% in total public health expenditures and an increase of only 0.9% in all (public and private) health expenditures.

Of course, implicit in these projections is the belief that uniform access to home-care funding, irrespective of region, is appropriate; that national standards should be developed outlining the range of publicly insured home-care services; that common eligibility conditions should be determined; and that common servicing plans should be drawn up once eligibility is determined. While it is a relatively straightforward matter to increase home-care funding, it is much more difficult to obtain agreement on the range of services that should be insured and to determine the precise terms and conditions of public insurance. Until these issues are squarely addressed at the national level, it is unlikely that progress will be made on a national home-care program.

### Conclusions

The tidal wave that has changed the Canadian health-care landscape over the last two decades has come to rest upon the shores of the home- and community-care sector. This turn of events has had an enormous impact on care recipients, their families and friends, and in-home service providers. The future age structure, health profile, and geographic distribution of the population, coupled with reductions in the supply of informal care, will result in increased pressure to fund professional home-care services.

The federal government has an important role to play in highlighting and addressing interprovincial variations in home-care funding, by introducing and enforcing national standards. Such standards should include many of the principles that support services privileged under the CHA. They should also outline the terms and conditions of public insurance, including eligibility, servicing plans, and cost-sharing arrangements. Finally, national consensus must be reached on the range of medically (and socially) necessary services subject to these standards, irrespective of the setting in which they are sought, received, and delivered, in order for Canadians to achieve optimal care in the 21st century.

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# **The Material and Social Predicaments of Home: Women's Experiences After Aortocoronary Bypass Surgery**

**Jan Angus**

Plusieurs auteurs prétendent que la vie des femmes est conditionnée par des circonstances sociales telles que la classe, la race, l'ethnie, l'âge, les capacités, la maladie ou l'incapacité chroniques. Il se crée des modèles d'avantages et de désavantages, de domination et d'oppression, qui constituent le terrain de la santé des femmes. Une ethnographie institutionnelle a été élaborée afin de suivre les expériences de 18 femmes qui ont réintégré leur domicile à la suite d'un pontage coronarien. Utilisant les récits de trois femmes comme exemples, l'auteure se concentre sur les activités quotidiennes des femmes au cours du premier mois de leur retour à la maison. L'auteure décrit les circonstances dans lesquelles se produisent ces activités et examine les relations sociales révélées par ces descriptions. À partir de cette analyse, on affirme que la recherche et le travail de fond bénéficieraient d'une compréhension plus critique de l'expérience différente des femmes relativement à la maison et aux soins à domicile.

Several authors argue that women's lives are conditioned by social locations such as class, race, ethnicity, age, and chronic illness or (dis)ability. Patterns of advantage and disadvantage, domination and oppression are formed which constitute the groundwork of women's health. An institutional ethnography was designed to follow the experiences of 18 women on their return home following aortocoronary bypass surgery. Using the narratives of 3 women as examples, the author highlights the everyday activities pursued by the women in the first month after their return home. The author describes the circumstances under which the activities occurred and discusses the social relations reflected in the descriptions. From this analysis it is argued that research and substantive work would benefit from a more critical understanding of women's different experiences of the home and of home care.

In Canada in 1999, women comprised 46% of the paid labour force and 68% of all mothers in two-parent families were employed (Statistics Canada, 2000). In the same year, women performed a disproportionate 65% of all unpaid labour (including volunteer work), a share that has remained stable since the early 1960s despite sharp increases in women's participation in the paid labour force. Women with children under age 19 and full-time employment spend from 1.5 to 2.5 more hours daily on housework than do their partners (Jackson, 1996;

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Statistics Canada). In 1999, women missed an average of 7 working days because of family responsibilities, compared to an average of 1 working day missed by men for similar reasons (Statistics Canada). These figures may actually underestimate the amount of time and effort women devote to homemaking and family care: the invisible labour involved in providing emotional support, maintaining links with health-care providers and educational systems, and coordinating social relationships with friends and neighbours are activities that escape the notice of time-usage surveys (Angus, 1994, 1996; Duncombe & Marsden, 1995; Luxton, 1997). In Smith's (1990) words, women's everyday lives consist in part of "localized activities oriented toward particular others, keeping things clean, managing somehow the house and household and the children — a world in which the particularities of persons in their full organic immediacy...are inescapable" (p. 20).

Statistical observations suggest that women may confront barriers when their own health requires time and attention. The literature on women's recovery from cardiovascular surgery and myocardial infarction is replete with references to resumption of homemaking tasks (Boogard, 1984; Fleury, Kimbrell, & Kruszewski, 1995; Hamilton & Seidman, 1993; King & Jensen, 1994; Sutherland & Jensen, 2000). Women are described in these studies as inextricably linked to homemaking by discursive concepts such as control, guilt, gender roles, and household responsibilities. However, these explanations do not acknowledge the ways in which women are differently constrained by social locations such as gender, class, race, ethnicity, age, and chronic illness or (dis)ability, or the myriad ways in which these locations articulate. Indeed, recognition of the deeply heterogeneous nature of women's material situations, identities, and experiences of health has marked a new approach to theorizing women's health (Clarke & Olesen, 1999; Doyal, 1995; Ruzek, Olesen, & Clarke, 1997). Scholars who draw our attention to the patterns of advantage and disadvantage, domination and oppression that condition individual women's experiences also would encourage us to consider how these patterns enter into everyday experiences of health and illness (Bannerji, 1995; Clarke & Olesen; Collins, 2000; Meekosha, 1998). Many Canadian authors draw attention to these patterns in their work on women with chronic health problems or (dis)abilities, and they consider how the relations of health care enter into the textures of their experiences (see, for example, Anderson, 1998; Anderson, Blue, & Lau, 1991; Dyck, 1995; Dyck, Lynam, & Anderson, 1995; Thorne, McCormick, & Carty, 1997).

With the above referents in mind, I will discuss the findings of an institutional ethnography of women's experiences on their return home

following aortocoronary bypass surgery (ACBS). Although many aspects of care, such as diagnosis, surgery, and post-surgical care, take place on the professional ground of doctors' offices, diagnostic laboratories, and hospitals, shorter hospital stays have resulted in an emphasis on the home as a location of recovery from surgery. I was interested in learning how women attend to their own health needs in a location where they are accustomed to arranging the conditions of health and well-being of others. In this paper, I consider how gender, age, class, and immigration configure illness experiences within the material and social context of home.

### **Analytic Framework**

The tenets of institutional ethnography (Smith, 1987, 1990, 1999) formed the analytic and methodological ground for this study. Smith explains that institutions are functional complexes comprising multiple locations wherein various activities are pursued by diverse actors (Grahame, 1998). The health-care system is a functional complex spanning locations such as hospitals, research institutes, government ministries — and homes. Potential difficulties inhere in the coordination of activities across these locations, yet individuals are able to proceed in collaboration despite distance, dissimilar foci, and a range of expertise. A fundamental assumption of institutional ethnography is that activities within institutions are discursively organized, and that discourse itself is textually mediated, or present in written materials, audiovisual media, and other forms of communication. Activities within the homes where women recover from cardiovascular surgery may be linked to the health-care system because of information conveyed at the time of discharge or through the presence of home-care providers.

Hence, people are discursively active in different places and in different ways. They remain embodied participants in discursively organized social relations within these various social positions. There are "differences in the possibility of knowing that relate to the knower's location and everyday/everynight work" (Campbell, 1998, p. 59). There are also some possibilities for the construction of codified knowledge which inevitably divest concepts of their underpinnings in the everyday. Hence, according to Smith, there are two modes of knowing. One arises in the local and particular world of embodied activity and the sensory organization of immediate experience. The other passes through or derives some elements from the local world but enters the more conceptual and generalized order of discourse. Concepts such as "gender role," which connects gender with the work of homemaking, are markers of the second mode of knowing.

Institutional ethnography is concerned with examining discourse or discursive practices and explicating the work or embodied activities that people pursue in the course of everyday life. The aim is to describe the social relations that are evident in how these local activities are linked and coordinated with work processes in other diverse sites (Grahame, 1998, p. 353; see also Smith, 1987). In this paper, I highlight the everyday activities pursued by women in the first month after their return home after ACBS. I describe the circumstances under which these activities occur and discuss the social relations reflected in these descriptions. I conclude by comparing these observations with the discourse on homemaking and gender which is evident in the nursing literature.

### *Study Design*

Experiential approaches to data collection are essential features of institutional ethnography because they enable the researcher to directly learn from the experiences of participants (Campbell, 1998). Hence, 18 women who were recovering from ACBS were purposively selected from the client group of the cardiovascular surgery department of a teaching hospital in a large metropolitan centre. These women were interviewed twice: once after they had been home from hospital for 4 weeks, and once after 4 months. The interviews followed an unstructured narrative format and were audiotaped and transcribed. Transcriptions were entered into the NUD\*IST software package for coding. Analysis closely followed the three-stage process reported by Kasper (1994), which she developed with reference to the tenets of institutional ethnography. The first stage of the analysis was completed by the respondents in their selection and interpretation of anecdotes or examples from a large repertoire of experiences. In the second stage, each woman's account was condensed into a biographical case study with attention to embodied activities and sensory perceptions as well as interpersonal experience. Luken and Vaughn (1997, 1999) use a similar comparative approach to biographical accounts. Review of these case studies led to development of a system of codes in the third stage of analysis, so that corresponding statements within transcribed interviews could be indexed, retrieved, and further compared.

Four distinct periods in the women's encounters with heart disease and treatment were evident in their narratives: diagnosis, hospitalization for surgery, the first month after surgery, and 4 months after surgery. Each point was suffused with social and bodily displacements or relocations. Diagnosis marked entry into the social category "women

with heart disease," which was connected to assumptions of moral responsibility for developing heart disease. Hospitalization removed the women from the familiar social context of home and close others, and embedded them within social relations that effected a sense of bodily dispossession. Homecoming was an occasion of relocation within a division of responsibility which was poorly designed to meet their needs and in which they were still responsible for the needs of others. In the months following their homecoming, the women struggled to situate themselves at the intersection of two, often conflicting, discourses: the discourse of homemaking and the discourse of self-care. For these women, illness and health care dislocated the binary spatial opposition of public and private, disrupting and rendering problematic the assumptive ordering of the home. Here, I focus on the women's initial period of relocation to the home after discharge from hospital.

### **Home: A Location of Healing for Women?**

On return to the site of their everyday world after hospitalization, respondents were confronted with a dilemma: their bodies and their physical health needs did not always align with the conditions and practices associated with home. This local world evoked biographical patterns of support for others, yet the moral responsibility to protect themselves and their own health presented a conflicting set of objectives. The women's physically healing bodies were a source of disturbing and sometimes mysterious sensory experiences that inhibited resumption of habitual activities. Instruction by health professionals, as well as information available through personal contacts, the media, or self-help books, had indoctrinated some of the women into a discourse of heart health that featured principles of risk modification and self-care. Yet the immediacies of home and the inescapable requirements of particular others presented another set of concerns. This was emphatically not simply a conflict of meaning; it was a material predicament centred on physical activity and the coordination of everyday life. Material and social circumstances influenced the range of possibilities available to each woman.

Thus, these women were no longer "at home" in their own bodies. Furthermore, they returned to everyday material and social conditions that provided varying degrees of convalescent support. Some were therefore more "at home" in activities that promote healing and recovery than others. They occupied an interstitial space created by the embodied and discursive intrusions of illness and health care into the assumptive world of the home, and it was their task to resolve the

resultant tensions. I turn now to discussion of how these conditions contoured the possibilities open to the women as they pursued care of their healing bodies in their own homes. Following Luken and Vaughn (1997, 1999), I will examine the narratives of individual women to illustrate that what each knew and could tell about managing the home in the early weeks after surgery was different, because each of the knowers occupied a different social location. The narratives of three of the women form the basis of this comparative analysis.

### *Social Relations of Homemaking After Surgery*

The activities of homemaking are extensive, and they do involve physical labour and exertion (Wilke et al., 1995). In the convalescent period following cardiovascular surgery, the women were advised to avoid heavy housework. They were instructed against lifting small children or otherwise placing tension on their healing sternums. Prior to discharge, their situations were assessed to determine the need for home-care support. Two women who lived alone with very limited assistance from their families were sent to convalescent settings for an additional week of care. Two of the 18 women received home-care services, including homemaking, upon returning to their own homes. But neither home care nor the presence of cohabiting family members ensured that the women were free to rest and pursue their own health needs. Their experiences were uniquely configured by their unique social locations.

*Eva.* A 75-year-old woman with arthritic joint deformities, Eva lived in a rented seniors' apartment with George, her 84-year-old husband of 2 years. She had been born and raised in Canada and was of European extraction. When Eva was admitted for surgery, George was also hospitalized, with thrombophlebitis. He was discharged home on anticoagulant therapy at the same time she was, and the couple received home-care services, which included nursing care for George, physical therapy for Eva, Meals-on-Wheels, and a homemaker to assist with personal care, cleaning, and laundry. However, it was Eva who coordinated her own and George's medications and health regimens, and it was she who called attention to his inflamed leg 1 week after discharge. He was immediately readmitted, and Eva's care regimen was interrupted by a new routine of hospital visits.

*Eva:* Okay, so there was also...a [physical] therapist was supposed to come in for me. [chuckles] And, um, I told her I wouldn't be able to see her that week because I had to go up to the hospital every day and walk through that tunnel...I got all the walking I needed. [chuckles]

Interviewer: Oh?

Eva: *And back home again... I stayed 4 hours with him and came back again at night... And when I was at the hospital I was up and down getting things for him. I thought I was getting enough exercise! She says, "You're right, you are! But we just want to show you how to walk." And I said, "Well, I've been through all that before."*

One week later, George was again discharged home and Eva described the embodied rigours of spousal caregiving. She found that her discomfort in the early weeks at home was in part associated with her responsibility for physical care.

Eva: *There was just, I think, the constant running... And then of course putting on those elastic stockings for him.*

Interviewer: *Oh, you put those stockings on for him?*

Eva: *Oh, yeah, and it was a struggle. Especially, it caught me all down here. [indicates sternal area]*

Her comments reflected careful coordination of George's many appointments for blood tests and assessment, as well as responsibility for his medication dosages:

*He has to have blood tests every solitary Monday they told him. And they always call me back... Last week I had to reduce his pills by two. I cut out Wednesday and Thursday. I'm expecting probably that they'll call me later on and tell me to do it again. And maybe he has to have the whole seven this week. He's on Coumadin.*

It was clear that the same attentiveness did not go into her own self-care efforts:

*I put the letter [from the cardiovascular surgeon to the family doctor] in my purse...and come to think of it I haven't given it to him yet.*

Here, gender and age intersect to create a position of disadvantage. Eva's story illustrates the consequences of a pattern of heterosexual bonding in which the woman is typically younger than the man. As both partners age, the wife often becomes involved in providing or coordinating health care for an older husband. Furthermore, older women's biographical experiences may facilitate development of considerable expertise in family caregiving. Eva, for example, had cared for her first husband when he developed severe coronary artery disease in middle age, and had nursed him after a subsequent stroke. In widowhood, her extensive experience with health professionals as she required treatment for arthritis and coronary artery disease further prepared her to assume responsibility for the care of her second husband, George. Her competence and ease with the language and practices of health care, as well as her eagerness to return home with her husband

regardless of the circumstances, may have led health professionals to view Eva as a candidate for home care rather than admission to a convalescent setting (Twigg & Atkin, 1995). In her narrative, George is described as more vulnerable than she, and he was not expected to provide care for her or to perform homemaking tasks.

*Margaret.* Younger women have different challenges and advantages. Fifty-three-year-old Margaret, like many women of her generation, worked outside the home for most of her adult life, and she raised her two sons to independent adulthood. Like Eva, she was Canadian-born and of European extraction. With her husband, Reg, she owned a large detached home in an upper-middle-class neighbourhood as well as a thriving family business. Her class location meant that Margaret was able to exempt herself from some of the activities of homemaking; she could afford the weekly services of a "cleaning lady." Margaret and Reg lived alone, and Reg was unable to stay home for lengthy periods to attend to her needs because their business was already short-staffed in her absence. Female family members were a constant caregiving presence during her first week at home:

*Well, my sister was here for a week with me. And Reg, he's fairly good at doing things, you know. And I have a cleaning lady come in once a week. So I had no problems, not really. And I had a daughter-in-law who was really, really great. Anything I needed she was there. They were always there when I needed — in fact, they were sometimes here too much and I'd tell them to go. [laughs]*

However, 5 weeks after her surgery Margaret returned to work. One facet of the business involved attending shows where some of their items would be displayed for sale. Reg and her eldest son had to attend one such show in another city and Margaret was left for a week to run the business with an employee:

*I went in with her...maybe from 12 to 5. I did it for the full week. I was kind of tired. I was really quite tired.*

Despite this pressure to maintain the viability of the business, Margaret insisted that she had the discretion, as co-owner, to decide which hours she would work. Consequently, she was able to develop a routine that included time for self-care:

*I exercise every morning. I walk. I always get up about a quarter to seven, half-past six, and I find I do like it. I've sort of got the house to myself and I do my exercise, my walking, in the morning, and I have my breakfast and I sit and really relax at this point. I don't go to the store until 11 o'clock so I can do a load of washing, whatever I have to do...I find*

*that first thing in the morning is my time, and that 3 hours, 4 hours, I just — my most important time is in the morning.*

Although this protected time included homemaking tasks such as laundry, Margaret did have the opportunity to read books and pamphlets about nutrition and, consequently, to experiment with her diet. She proudly reported her progress:

*I eat properly. I don't take sugar any more, I don't put salt in my food. I use herbs, and I don't eat anything that's fat. I stay away from the fats, although I try to have the good fats, which I should have. And my cholesterol has been good, and my blood pressure is fine, so I guess I'm fine for a while. [chuckles]*

Margaret's class location brought advantages and disadvantages. She could afford to pay to have her house cleaned, and she could, to some extent, determine her own working hours to suit her health needs. She lived in a large, comfortable house in a safe and quiet neighbourhood. Yet she was also bound to the staffing demands of her family business. Margaret's experiences were also embedded in social relations that were marked by the continuing devolution of caregiving work from paid providers to unpaid family members — in her case, a sister and daughter-in-law. These female relatives were a continuous presence during her most vulnerable period so that her husband could attend to the family business. Her use of the phrase "I have a cleaning lady" was a further reference to social relations that configured her experience but that were not immediately apparent in her everyday world. The phrase is a code that conceals with its simplicity the relations of purchasing house-cleaning services from another woman at affordable rates. Both instances disrupt the boundaries of public and private, formal and informal, paid and unpaid, and reveal the entanglement of the local world of home with extralocal relations.

**Olga.** A 50-year-old self-declared housewife, Olga told a story that differed from Margaret's, despite their similar ages. When she was 18, she met and married her Latino husband in her native Germany. The first of four children was born a year later, and the family moved to Canada when she was 22. She became unwell in her mid-40s but found it difficult to engage the attention of her family physician to the sensory experiences, which she interpreted as severe fatigue and, later, shortness of breath.

*Instead of finding out why I was complaining, he told me to find a job. Then finally he eventually did find out that I had diabetes. I had no idea. And so this is the same story now — he kept on saying, "Oh, there's nothing wrong with you." I was somehow in the background of my mind*

*always worried...thinking of my father [who died of heart disease]. That always worried me. That might be something there with the heart. And also he told me to stop eating sausages. [laughs] Maybe because I'm German he thought I eat morning, night, and all day long sausage.*

Olga's social locations as a housewife and an immigrant entered into the diagnostic process. Because she was a housewife with a nearly empty nest, she was presumed depressed and in need of a diversion. Because she was an immigrant, her dietary patterns were imputed by her physician to be culturally distinct and problematic, yet her physical symptoms were not investigated.

Olga confided at the beginning of our first session that she was embarrassed by her accent and had occasional problems selecting or understanding English words. Although she could fluently speak and read the language, she told me that it was difficult for her to write in English and this had impeded her efforts to secure and retain the kind of employment that interested her. Eventually she had given up her search for work outside the home. She explained that these linguistic issues also constituted a barrier to her obtaining information. Indeed, our discussions were punctuated with her pauses as she tried to identify or define the appropriate term:

*I mean, we are immigrants...we didn't even know that word, and so we never used it.*

Olga: *And then he explained that day before the surgery where they take the vein, you know, this... [pause] But still, I'd like to know more about that. And I've never heard about this, what's it called — memory...?*

Interviewer: *The mammary artery?*

Olga: *I'd never heard about that, and I just can't picture how this all works... I'd like to know about these things.*

These statements describe the constraints Olga encountered in her efforts to gather information about her treatment, but they also remind us that the interview is, among other things, "a site of identity negotiation" (Dyck, 1998, p. 26), whereby participants "place" themselves and one another within a social framework. Olga's comments and our discussion identify her as an immigrant and me as somewhat representative of the health professionals who possessed the linguistic skills and information to which she had limited access. Her efforts to learn the vocabulary associated with her diagnosis and treatment underscore the exclusionary power of language and the fact that the construction of shared social worlds is mediated by shared terminologies (Smith, 1999). Unlike Eva, with her long history of communicating with health pro-

fessionals, and Margaret, with her effortless reading of publications on cardiovascular risk reduction, Olga struggled to interpret the implications of her illness for her personal care.

Olga described other conditions that limited her possibilities. Her husband was the sole wage earner, and his working-class location as a lathe operator made the couple vulnerable to a competitive global climate in the industry in which he worked. Periods of intense labour resulted in overtime and increased income, but layoffs were also common:

*Until a few months ago, from about late summer last year, they had so much work to do that he had to work 7 days a week. And that never, ever happened. Until that all stopped — not so wonderful for the pocket, you know, not at all. [laughs] And we never learn. When there are times of plenty, you don't put some on the side. And now suddenly there is this big bang, and there is not enough. But that's life.*

Her husband was called back to work when Olga was ready to be discharged from hospital:

*My husband was willing to stay home with me but we just totally couldn't afford it. I don't know how to pay the bills after if he had, because he's paid by the hour. And the week before the surgery he hadn't been working.*

In the traditional division of domestic responsibility in Olga's household, an adult son who was still living at home was not expected to provide homemaking support. Instead, her daughter returned home from university studies in another city to care for her mother for a brief period before taking a scheduled trip to Europe:

*She was here for a while and then she got an occasional 2-week job, and she really needed that because Europe is very expensive right now. So she went for that job... That's when I started to do all the housekeeping here again, but this is even though I got the shouts from my husband: "What are you doing? You're crazy, don't do it!" But nobody else did it, so what are you going to do? And he is tired...he's even more tired now than when he worked 12 hours a day. So who else is going to do it? I think all these things are better for men because they get served anyway. But women...things totally get screwed up if they're not — if you're not in charge, you know.*

As Olga pointed out, a vacancy existed within her home. There was no other person present who was consistently able or willing to run the household while she recovered from her surgery. Indeed, in the uncertainty associated with extralocal influences on their income, she was concerned to ensure that her husband was able to rest after his day of labour. Such homemaking ensures the continuous availability of a func-

tioning labour force. Hence, Olga was bound by her financial dependency on her husband to her position as an unpaid participant in social relations that support and constitute the economy. She could not find the office or retail work she favoured because, as an immigrant, she was unable to write English. Her schooling and vocational preparation had been terminated by early marriage and motherhood, further limiting her options.

These case studies illustrate the importance of beginning analysis from the standpoint of women's embodied activity within their everyday worlds, but also of attending to the ways in which experience is conditioned by interlocking social locations such as gender, age, class, and immigration. These locations did not determine experiences, but interacted to present barriers or opportunities as the women managed tensions arising from the embodied and discursive intrusions of illness and health care into the assumptive order of the home. The women's accounts permit us to glimpse the local manifestations of the social relations of health care, which articulate with gender, age, class, and immigration. When women are deemed in need of home care, services are purchased by the state from providers of personal care and homemaking, while residual needs are fulfilled on an unpaid basis by family members or the women themselves. Women who are not considered candidates for home care either rely on the assistance of family members or purchase cleaning and caregiving services with their own resources. Yet some women, despite their own health concerns, are economically dependent on spouses who require rest at the end of a day's labour, or must attend to the residual unmet needs of older, frailer others. In such instances, the women become not only their own caregivers, but homemakers and caregivers to others. Furthermore, it has been noted that access to the information needed to make decisions about personal care may be severely limited by language barriers and hierarchical relationships between immigrant women and health professionals (Anderson, 1998). Such relations exacerbate tensions within the home and result in differential access to health care.

### **Conclusions**

Although shorter hospital stays are intended to result in financial savings for governments and hospitals, this solution ignores persistent gender inequities in the distribution of domestic work. It evades the problem of providing care, homemaking assistance, and financial support to the family caregiver who is ill herself. It presumes that other family members will know how to "take over" for her, and will be

available and willing to do so (England, Keigher, Miller, & Linsk, 1994). But gender inequities perpetuated in home-care policies and practice are not the same for all women. Various social and material circumstances contoured the patterns of advantage and disadvantage experienced by the women who participated in this study.

There is a lack of cross-pollination between the social sciences literature on housework and the health sciences literature on women and cardiovascular disease. In the social sciences, there is an evolving understanding of how the politics of gender are enacted in the everyday work of homemaking. Doyal (1995), for example, casts this problem within the framework of the global politics of women's health. She argues that the health of all women is affected in various ways by the demands of home and family. Although North American women do not need to spend hours in a physically exhausting search for food, fuel, and clean water, their health is affected by the "double burden" of paid employment and homemaking. This burden results in drastic limitations on the amount of time available for rest, leisure, attention to personal health, and pursuit of information about healthful activities. Efforts to "shift" that burden by employing others inevitably rely on the exploited labour of other women, who are remunerated at minimal rates for their undervalued work.

Authors writing from a health sciences perspective seem less certain about the problems involved in housework: "Clearly, in this study women were engaged in fairly strenuous household duties (eg., bed making, laundry, and sweeping), within 4 weeks after experiencing an AMI. Whether this is beneficial or harmful has not been investigated" (Hamilton & Seidman, 1993, p. 313). Some do venture further into the discussion: "Although domestic functions are of high value to women in perception of self, they are poor choices of cardiovascular activity for women" (King & Jensen, 1994, p. 104). Successful engagement in homemaking tasks is very easily, but tautologically, construed as constitutive of gendered identity because these tasks are incorporated within an assumptive and persistent "natural" gender division of labour. Furthermore, the problem is often discursively elaborated in the health sciences literature as one of cardiovascular exertion. Within this idiom, the question becomes one of exercise, not equity, and the subtly inscribed dynamic is one of "choice." This is a seductive perspective, for it leads us away from the challenges associated with confronting the fundamental structures of social life. It obscures from our view how very few choices some women have and — more distressingly — how we may, with the best of intentions, participate in social relations or professional activities that further limit these choices or obscure the

scarcity of options. We are thus spared the difficulties of figuring out how we, as nurses, are to respond to the very real effects on health of the intersecting conditions associated with gender, class, race, ethnicity, age, and (dis)ability.

We can begin by considering homemaking as something more than simply an example of "gender role" performance or identity, although many aspects of the everyday construction of selfhood reverberate within these ideological codes. A home is a place where all the immediacies of material and social continuity intersect for all of its inhabitants. Our attention needs to be focused on these intersections and how they are experienced by particular women as they struggle with the conflicting demands of physical discomfort and infirmity, learning new personal-care regimens and coordinating contact with various facets of the health-care system. Our teaching interventions might then go beyond instructing women to "say no" to housework after surgery and become an attempt to learn the reasons why they actually may be compelled to resume this work. Discussion about cardiac risk modification might then expand into a dialogue about "the hazards of hearth and home" (Doyal, 1995, p. 27) which takes into consideration the possibility that the same home may be a very different place for its various occupants.

As Olga points out, men and women may have very different experiences of the purposes and responsibilities inherent in being "at home." Her observations make it clear that we nurses cannot assume that we necessarily share our patients' experiences of home. The home is a crucial location as it becomes more and more entangled within the institutional complex of health care, and it is a problematic location in that its metaphorical significance distracts us from the very real social and material conditions that intersect within it. It is vital that we increase the complexity of our theoretical approaches to the home as we enter this sphere in our research and practice endeavours.

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## **Perceived Support Needs of Family Caregivers and Implications for a Telephone Support Service**

**Jenny Ploeg, Laurie Biehler, Kathleen Willison,  
Brian Hutchison, and Jennifer Blythe**

Les objectifs de cette étude étaient : de déterminer les besoins de soutien perçus par les membres de la famille fournissant des soins aux personnes vivant avec une maladie chronique (physique ou cognitive) et recevant des services à domicile, et de décrire les types de services téléphoniques qui satisferaient ces besoins. L'étude qualitative a utilisé des entrevues semi-structurées. Au total 34 fournisseurs de soins (âge moyen : 62 ans) ont participé à l'étude. Les bénéficiaires (âge moyen : 78 ans) étaient surtout les époux ou épouses ou des parents des fournisseurs de soins. Les besoins des fournisseurs de soins les plus souvent exprimés ont été : une vie sociale, du soutien instrumental (une relève, de l'aide pour les soins physiques, une compensation financière), informationnel et affectif. La majorité des fournisseurs de soins ont affirmé qu'ils utiliseraient un service de soutien téléphonique fourni par un professionnel (71 %) ou par un autre fournisseur de soin (59 %), s'il en existait un. Les résultats de cette étude commandent une étude pilote et une évaluation quant à un service de soutien téléphonique destiné aux fournisseurs de soins membres de la famille.

The purposes of this study were: to identify the perceived support needs of family caregivers of persons living with chronic illness (physical or cognitive) and receiving home-care services, and to describe the types of telephone services that would meet the expressed needs of caregivers. The qualitative design used semi-structured interviews. A total of 34 caregivers (mean age 62 years) participated in the study. The care recipients (mean age 78 years) were primarily the husband / wife or parent of the caregiver. The most commonly expressed caregiver needs were: a social life, instrumental support (e.g., respite, assistance with physical care, financial compensation), informational support, and

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emotional support. Most caregivers said they would use a telephone support service provided by a professional (71%) or a fellow caregiver (59%) if available. The results of this study support a pilot study and evaluation of a telephone support service for family caregivers.

The recent restructuring of the health-care and social service systems has resulted in a major shift to care in the community, increasing the burden on informal support networks of family and friends (Grunfeld, Glossop, McDowell, & Danbrook, 1997). As the stress on caregivers grows, they are increasingly in need of support services. Telephone support offered as part of home-care services and provided by professionals or fellow caregivers may be a relatively inexpensive and effective strategy to help meet caregiver needs. However, there is limited information about the perceived needs of caregivers and their preferences with regard to telephone support services.

This paper describes a study of the perceived needs of those providing care to persons with chronic physical or cognitive illness and receiving home-care services, as well as the types of telephone support services that might meet those needs. The study was supported by a partnership of academic and community agencies in the province of Ontario, Canada, including Community Care Access Centre (a home-care agency), a branch of the Victorian Order of Nurses (VON), McMaster University, and a regional caregivers' network.

### **Background**

Canada's growing elderly population, budget constraints, and technological advances have led to major health-care reforms (Bergman et al., 1997). Inpatient hospital stays have been reduced in length, the number of nursing home beds has decreased, and the priority in home care is shifting towards post-acute services and away from long-term care (Merlis, 2000). There has been a major shift in care to the community, increasing the burden of care on informal support networks of family and friends (Grunfeld et al., 1997). Informal caregivers are largely responsible for providing care to the increasing proportion of community-dwelling older persons who are frail and suffer from chronic illness or cognitive impairment.

Many Canadians are involved in caregiving. According to the 1996 General Social Survey (Statistics Canada), 11% of the population 15 years and over (more than two million people) provide an average of 4 to 5 hours of informal care per week to seniors with long-term health problems (Keating, Fast, Frederick, Cranswick, & Perrier, 1999). Most of

the caregivers of those with long-term conditions are middle-aged women, though many seniors also provide informal care (Cranswick, 1997). This burden on women is exacerbated by the increasing participation of women in the workforce. Chappell (1992) found that 80% of care for older seniors is provided by family and friends. Recipients of care are most frequently parents or spouses of the caregiver.

The informal caregiving networks are, however, often "overextended or at risk of breaking down" (Bergman & Beland, 2000). Caregivers bear physical, psychosocial, and economic burdens that negatively affect their quality of life (Grunfeld et al., 1997; Keating et al., 1999). The 1996 General Social Survey notes that 45% of caregivers have modified their social life as a result of caregiving duties, 44% have incurred financial costs because of their responsibilities, 29% report changes in their sleep patterns, and 21% report that their health has been affected (Cranswick, 1997). Furthermore, mental or emotional strain has been found to be an independent risk factor for mortality among older spousal caregivers (Schulz & Beach, 1999). Not only does caregiver burden reduce quality of life, it also limits the effectiveness of the informal support system for at-risk older adults, and it may contribute unnecessary costs to the health-care system.

The needs of caregivers have been examined. In a review of the 1996 General Social Survey, Cranswick (1997) found the greatest informal caregiving needs to be respite, financial compensation, information, and counselling. The support needs of informal caregivers vary with their own stage of life, the length of time they have been a caregiver, and the acuity and intensity of the caregiving situation (Norbeck, Chafetz, Skodol-Wilson, & Weiss, 1991). For example, the needs of those providing 24-hour care on a long-term basis differ from the needs of those dealing with an unexpected diagnosis or a sudden crisis for the care recipient.

The effectiveness of interventions for caregivers has been assessed in two systematic literature reviews. Knight, Lutzky, and Macofsky-Urban (1993) conducted a meta-analysis of 18 studies of interventions for caregiver distress. The interventions included respite services and individual and group informational and support services. The authors concluded that respite services and individual psychosocial interventions were moderately effective but that group psychosocial interventions were not very effective. Tilford, Delaney, and Vogels (1997) reviewed studies of the effectiveness of mental health interventions for long-term caregivers of highly dependent people. They concluded that

some psychosocial interventions to promote support and coping can help to reduce caregiver stress. Little research included in either review addressed the role of peer/volunteer support and none of the studies examined telephone support for caregivers.

Telephone support has been proposed as a cost-effective alternative means of delivering selected home-care services (Short & Saindon, 1998; Shu, Mirmina, & Nystrom, 1996). It can be delivered at convenient times, with privacy, and can be tailored to the needs of the individual (McBride & Rimer, 1999). One of the major advantages of telephone support is that it can conveniently fit into the lives of burdened caregivers who may be housebound with very little time in their day in which to seek and receive support (Goodman & Pynoos, 1990).

There have been three recent systematic reviews of the effectiveness of telephone services for various groups of people. McBride and Rimer (1999) reviewed 74 randomized trials in which the telephone was used to deliver a primary or adjunctive component of a health-related intervention. Telephone interventions were found to be most effective in promoting lifestyle changes and in appropriately reducing the number of face-to-face clinical encounters for patients with chronic illness who were high users of health services. However, most of the studies reviewed did not allow for the telephone component of the intervention to be evaluated separately from other components.

Hoxby et al. (1997) conducted a review of eight randomized trials of the effectiveness of telephone services for patients with various chronic illnesses. They concluded that the studies showed some evidence of the effectiveness of this intervention for physical and social health as well as decreased health-care utilization and costs.

Cava et al. (1999) carried out a review of the effectiveness of 12 telephone interventions within the scope of public health nursing. The results suggest a positive impact on physical health, psychological health, knowledge, health-related behaviours, and health-resource utilization. However, the methodological rigour of those study designs was limited.

While these three systematic reviews suggest that telephone interventions have a positive impact on the physical and psychological health, health behaviours, and health-resource utilization of patients, few studies have examined the effectiveness of telephone services for caregivers. A randomized controlled trial by Goodman and Pynoos (1990) compared two types of telephone intervention for caregivers of persons with Alzheimer disease. One group received a peer-support

intervention in which groups of four or five caregivers would phone each other on a rotating basis for 12 weeks. The other group had access to taped informational lectures on Alzheimer disease over a 12-week period. Both types of intervention resulted in greater satisfaction with social supports.

Other studies of the effectiveness of telephone interventions in providing caregiver support have used less rigorous designs (Brown et al., 1999; Coyne, 1991; Davis, 1998; Skipwith, 1994; Strawn, Hester, & Brown, 1998). Brown et al., using a quasi-experimental design, found that a telephone support group was as effective as an in-person support group in providing support and education to caregivers. In a feasibility study of a telephone intervention using a before/after design, Davis found a significant reduction in caregiver depression scores, an increase in life satisfaction, and increased use of social support.

Despite the limited evidence of the effectiveness of telephone services for caregivers, there is some evidence that caregivers favour them. Colantonio, Cohen, and Corlett (1997) conducted a telephone survey of 84 caregivers from the Alzheimer's Society of Metropolitan Toronto Wandering Persons Registry. Only 8% used telephone support services, but 57% of non-users said that they would like to do so.

### **Purpose**

This paper addresses two research questions: *What are the perceived support needs of family caregivers of older persons who are living with chronic illness and receiving home-care services? What types of telephone support services would meet the perceived needs of caregivers?*

### **Methods**

#### ***Sample***

Case managers of a home-care agency in Ontario were invited by a member of the research team (also a case manager) to participate in the study. Case managers who volunteered to take part were asked to review their caseloads and identify caregivers who met the following criteria: 21 years of age or older; currently providing care for an adult (21 years or over) with a chronic illness (physical or cognitive) and receiving home-care services; has been providing care for at least 6 months; speaks English; and is not a caregiver for a person with a palliative condition such as end-stage malignancy. The intention was to select typical caregivers who provided substantial or complex care and

represented a spectrum of caregiver characteristics. Case managers referred caregivers to the project from October to December 1999. From the client lists provided by case managers, two of the investigators selected a sample that represented diversity in four major categories: caregiver gender (male and female), age (younger and older), and location (urban and rural), and care recipient age (younger and older). The case managers then called the selected individuals and, using a prepared script, asked permission to release their name, address, and telephone number to the research team. A letter describing the study was sent to each subject. The interviewer (project research assistant) contacted caregivers within 1 week of receipt of the letter to arrange a time and place for the interview. Subjects could refuse to participate at a number of points in the study: when the case manager called for permission to release their name, address, and phone number to the investigators; when the interviewer contacted them by phone; or, once the interviewer arrived, at any point before or during the interview. When a caregiver refused to participate or could not be contacted, the investigators selected another potential participant from the case manager client lists.

Three caregivers could not be contacted by the case managers, three refused to participate due to illness, and three refused to participate without giving a reason. Six caregivers who had agreed to take part could not be contacted by the interviewer. When 34 interviews had been conducted, the research team agreed that no new information was being obtained and that the topic was saturated.

### *Interviews*

A semi-structured interview schedule was developed to provide detailed information about caregiving responsibilities, perceived needs, and preferences related to telephone support services (see Table 1 for examples of questions). The interview schedule was pilot-tested with seven members of a regional caregivers' network and was revised based on their recommendations.

Caregivers were interviewed in their homes ( $n = 27$ ), in the VON office ( $n = 4$ ), or by telephone ( $n = 3$ ). Interviews lasted between 30 and 90 minutes with an average length of 60 minutes. The interviews were carried out by a research assistant (RA) with a background in gerontology. The principal investigator accompanied the RA on two interviews and provided feedback and strategies to enhance the richness of data collection. The interviews were audiotaped and transcribed.

## **Data Analysis**

After the tapes were transcribed, the transcripts were reviewed and cleaned by the RA. Replies to open-ended questions were subjected to thematic analysis (Boyatzis, 1998). Four texts were coded independently by two members of the research team and the results were compared. Input was also received from other team members and any differences in coding resolved by consensus. A coding scheme was established and became the basis for coding the remaining texts. Additional codes were added as required. The coding scheme revealed themes identified by the interviewees and provided the structure for reporting the results of the interviews. The research team discussed and reached consensus on the themes identified. A preliminary report of the results of the study was reviewed by members of the regional caregivers' network, who confirmed the identified themes. The study received ethical approval from the McMaster University Research Ethics Board.

**Table 1** *Examples of Questions from Interview Schedule*

Tell me about the kinds of care you provide.
Tell me a little about how you feel as a caregiver.
Some people find that there are both positive and negative aspects of caring. Tell me more about your experience.
What do you see as your most important needs as a caregiver?
What kinds of support do you receive to cope with these things?
In what areas would you like more support as a caregiver?
Which of the needs you identified could be met by some type of telephone support service?
Tell me about any advantages or disadvantages you see in receiving telephone support.
In what situations would a professional (or fellow caregiver) be the best person to help you?
If a telephone service was available, is there anything that would keep you from using it?

<b>Table 2</b> <i>Characteristics of Caregivers (n = 34)</i>	
Characteristic	Number (%) of Caregivers
Age	Range: 34–81 years Mean: 62.3 years; SD = 13.6 years
Gender	
Female	22 (65)
Male	12 (35)
Marital status	
Married	24 (71)
Single (never married)	3 (9)
Divorced	3 (9)
Widowed	2 (6)
Common-law	2 (6)
Highest level of education completed	
Less than Grade 9	5 (15)
Some high school	12 (35)
Completed high school	7 (21)
Some college or university	2 (6)
Completed college or university	8 (24)
Employment status	
Employed full-time	5 (15)
Employed part-time	4 (12)
Not employed /retired	25 (74)
Household income	
Less than \$20,000	4 (12)
\$20,000 to \$29,999	6 (18)
\$30,000 to \$39,999	9 (26)
\$40,000 to \$49,999	3 (9)
\$50,000 to \$59,999	2 (6)
More than \$60,000	3 (9)
Unknown/declined to answer	7 (21)
Size of household	Range: 1–6 members Mean: 2.5 members; SD = 1.0
Self-rated health	
Excellent	5 (15)
Very good	5 (15)
Good	16 (47)
Fair	8 (24)
Poor	0

Findings

The findings are presented in three sections: sample characteristics, perceived support needs of caregivers, and caregiver preferences related to telephone support.

Sample Characteristics

The characteristics of the 34 participating caregivers are described in Table 2. Their mean age was 62 years and most were female, married, and retired or not employed. Three quarters of the caregivers reported their health as excellent, very good, or good.

The 34 caregivers provided care for 36 care recipients, with two caregivers looking after two people. The characteristics of the care recipients are summarized in Table 3. Their mean age was 78 years and most were female and married. Most were either spouses (more husbands than wives) or parents (more mothers than fathers) of the caregivers. All had been diagnosed with a chronic physical or mental health

Table 3 Characteristics of Care Recipients (n = 36)	
Characteristic	Number (%) of Caregivers
Age	Range: 34–93 years Mean: 78 years; SD = 10.9 years
Gender	
Female	19 (53)
Male	17 (47)
Marital status	
Married	21 (58)
Single (never married)	1 (3)
Divorced	1 (3)
Widowed	13 (36)
Common-law	0
Relationship to caregiver	
Husband	12 (33)
Wife	5 (14)
Mother	12 (33)
Father	5 (14)
Child	1 (3)
Sister-in-law	1 (3)

problem. The most common condition was Alzheimer disease ( $n = 13$ ), followed by stroke ( $n = 10$ ), heart condition ( $n = 8$ ), and arthritis ( $n = 3$ ). All received homemaking services and approximately 50% received nursing services.

The caregivers had been providing care for between 1 and 15 years ( $mean = 5.3$ ,  $SD = 3.5$ ). Twenty-nine recipients lived with the caregiver. All the caregivers considered themselves the primary care provider but only three considered themselves the sole provider. Twenty-five caregivers (74%) said that they provided care on a 24-hour basis. Six said they provided daily care and three said they provided less than daily care. In most cases the caregiver cooked, cleaned house, shopped, took the care recipient to doctor and hospital appointments, and managed household finances. Caregivers supervised or administered medication. Some carried out health-care procedures such as suctioning and tube feeding. The most disabled recipients required assistance with the basics of self-care such as dressing, eating, washing, toileting, and incontinence care.

### *Perceived Support Needs of Caregivers*

Caregivers reported their most important caregiving needs, which resulted in the identification of four themes: the need for a social life, the need for instrumental support, the need for informational support, and the need for emotional support. No differences in perceived support needs were found between male and female respondents. The excerpts below are taken verbatim from the record of each interview.

*The need for a social life.* The caregiver need most commonly expressed was the need for a social life. Many caregivers described a life of social isolation. They no longer went out in the evenings or visited with friends or family. Even when they did go out, they were often preoccupied with thoughts of the care recipient. While some caregivers had visitors, others found that their social circle had "dwindled away." Some visitors had stopped coming because they were upset by the care recipient's illness. Many caregivers could leave the care recipient only while a homemaker was present or if the care recipient went to a day program:

*My social life has decreased. Even last year she couldn't get up from bed, so it was worse last year because I just couldn't go out. I was always in the house... [My social life] is nil, has decreased to nil. (Caregiver #10)*

*I just find they don't come around the same because my husband can't talk to the fellows, and these are friends that we've had for 35 years. That*

*I find the hardest part...socially... I just don't see or hear from them. They always think, "Well, I don't want to call you because [you're] busy." Well, call, I'll take 5 minutes to talk to you... And when I go out I don't want to talk about it. I'm out for a good time. I want away from it. Like, that's even these support groups. I went yesterday to see what it was about. It's how to be a caregiver and survive it. I came out shaking my head — like, why did I bother going... I want to go out and have fun for an hour. I live this all the time. I don't want to go out and live it again. (Caregiver #8)*

The care recipient was usually the caregiver's most consistent companion. It is not surprising therefore that caregivers felt "like running away" or needed "space" or felt "trapped." Almost all caregivers craved more time away even if they worried about the care recipient when they were absent:

*Sometimes I feel like if I could run away from home I would do it...just for more time to do a little bit with my husband...just to be able to go away for a weekend...or a couple of days and not worry. (Caregiver #9)*

*I have no social life. I'm really tied down... We used to square dance five to seven nights a week. Life has really changed... We don't get to go to Florida any more... All our friends were basically square dancers so I don't see them any more... I miss the social life and the friends. You feel sort of cut off. (Caregiver #31)*

**The need for instrumental support.** The second theme related to perceived caregiver needs was instrumental support. Caregivers identified the need for increased caregiver relief, assistance in providing physical care, and reimbursement for financial costs related to caregiving. They pointed to the need for more hours of professional or non-professional support in the home:

*I know I'm getting tired and I do need a break from it...I would like to see them come into the home [to give respite]... Certainly more hours [of support would help]. I'm not complaining, I appreciate what I have, but it's long days. It is long days. (Caregiver #8)*

*They've cut me down to 2 hours a day for 4 days only, and that's really not enough. (Caregiver #26)*

Caregivers stated that they needed more support with physical care, such as lifting and moving:

*The physical exertion...in the caregiving. She used to weigh 130 pounds. Now, because she's totally immobile, she's 170 pounds and it's difficult for me as an older guy, even with my size, to lift her from the bed onto the commode and back... [I would like more help with] just the physical support, somebody to do the heavier physical stuff. (Caregiver #27)*

Caregivers also noted the need for financial support. They spoke about the financial impact of providing care, such as out-of-pocket expenses and lost wages:

*I guess financially speaking everybody could always use a little extra, because you have a lot of expenses that you didn't realize you were going to have with this situation. I mean, just diapers are \$100 a month. Stuff which you hope you never have to need but... [When my mom] had her injury, we had to bring some aids in for her, like a bath chair. Stuff like that. We ended up buying it, so that was \$200. And her medication unfortunately isn't covered because it's viewed as a new medication. (Caregiver #16)*

**The need for informational support.** The third theme related to perceived caregiver needs was informational support. Caregivers stated that they needed to have more information about the care recipient's illness and how to manage it:

*I just want somebody...when I see that crazy sugar so high I worry about it. If I have somebody who understands about what I can do... (Caregiver #1)*

*I would have liked to know what other people are doing. I know each case is different, but if there's somebody else doing the same cases as my husband, what are they doing to help out? (Caregiver #3)*

*If there was a problem, let's say if Dad was having difficulties, cognitive difficulties like dealing with where he was, I'd like to [say] this is happening, where do I go from here?... If there was somebody in the middle of the night that you could phone...just be able to talk to somebody for a bit. (Caregiver #6)*

Caregivers also indicated a need to know more about community health and social support services available to them:

*Somebody's got to tell me who accepts Alzheimer patients in this area...it's very difficult to place them... [By] the same token, someone's got to tell me...on an emergency basis — if I have a heart attack or something — who steps in immediately...someone has to step in immediately, because she can't stay here alone. (Caregiver #4)*

**The need for emotional support.** Some caregivers expressed the need for emotional support in dealing with the demands of caregiving:

*You get everything inside, inside, inside, and then it has to come out. And the only way it's going to come out is if you cry and everything comes out. Yes, there are times I do need people to go to and talk about those things, to express my emotions. Yes, it's good. (Caregiver #10)*

*...to get emotional support in the beginning [of caregiving] because, boy, when it hits it really hits you... Everything that you were feeling, possi-*

*bilities of what could be done, possibilities of what could happen again. I'm not sure that it was only feelings, but just to know somebody is there that you can totally rely on, because you feel like you're going to crack up yourself. (Caregiver #18)*

### ***Caregiver Preferences Related to Telephone Support***

Caregivers were asked about their previous experiences with telephone support and their opinions about such services. Three respondents had used a telephone service provided by a professional and one had used a telephone service provided by a fellow caregiver. Twenty-four caregivers (71%) said they would make use of a telephone service provided by a professional if available, seven (21%) said they would not, two (6%) were unsure, and one did not answer the question. Twenty caregivers (59%) said they would use a telephone service provided by a fellow caregiver if available, nine (26%) said they would not, two (6%) were not sure, and three (9%) did not reply to the question.

Twelve caregivers (35%) said they would like to initiate calls to a service and two (6%) said that they would like the caller to do so. Thirteen caregivers (38%) favoured a combination of the caller and themselves initiating calls. Only two of the 28 caregivers who responded to this question said they would prefer to remain anonymous while receiving telephone support. Caregivers indicated that telephone support could potentially meet some of their informational and emotional needs. Three themes related to telephone support were identified in the data: different roles of professionals and fellow caregivers in providing telephone support; preference for knowledgeable, well-trained, caring telephone service providers; and the need for after-hours support.

***Different roles of professionals and fellow caregivers in providing telephone support.*** Caregivers saw professionals and fellow caregivers as playing different roles in the provision of telephone support. They viewed professionals as better able to offer disease-related information and assistance in emergencies. They recognized the ability of fellow caregivers to give advice based on experience and to provide emotional support:

*I think a fellow caregiver would be supportive and understanding. I think the professionals would be more for specifics like medicine and finding out what agencies are out there for help. (Caregiver #15)*

*A fellow caregiver it would be when you have your low points you would call for support. A professional...might be the same thing, but it would*

*also be if anything happened, a change in condition [of the care recipient]...to confirm that I'm doing the right thing. (Caregiver #18)*

*Professional people are fine but they don't deal with the caregiving of a person. I'm not trying to be smart by saying that...a person who does it all the time at home knows what you feel instead of a professional who doesn't deal with it. (Caregiver #9)*

**The need for knowledgeable, well-trained, caring telephone service providers.** Caregivers stressed that it was important the telephone service providers be knowledgeable, well trained, and caring, capable of developing rapport with the caregivers:

*The person that answers the phone...has to know exactly what the person needs. He can't give him the wrong information. So it's got to be a very well trained person. (Caregiver #2)*

*I think that people on the other end of that service are going to have to be...understanding and caring people. (Caregiver #15)*

*If I'm going to phone a person up...and the other person, a caregiver, is in the same boat as I am — they don't know what they are doing — how are we going to help each other? Even the volunteers sound good, but is the volunteer, he/she, going to be trained to be able to answer...? (Caregiver #10)*

**The need for after-hours support.** Many caregivers identified a need for after-hours support for relief and emergencies — that is, outside of the normal community agency hours of 9am to 5pm on weekdays. Many caregivers emphasized their need for help at night and on weekends:

*The nights are long...if there was somebody in the middle of the night that you could phone...just to be able to talk to somebody for a bit. (Caregiver #6)*

*When I feel the worst is in the middle of the night when I'm having problems... There are times when I need it [support] at night, in the evenings. (Caregiver #31)*

*I would say 7 days a week, 24 hours a day, but that's probably not very realistic. Probably just not 9 to 5, maybe 8 to 8 or something like that...a 12-hour period. And at least 1 day on the weekend I think is important for people, especially if you emotionally need that support. Sometimes the weekends are the hardest time to get in touch with people... It would be nice to know that they are available. (Caregiver #16)*

## Discussion

The caregivers in this study expressed a need for a social life, instrumental support (e.g., respite, help with physical care, financial com-

pensation), informational support, and emotional support. Some of these perceived needs are consistent with the needs identified by Cranswick (1997), from the 1996 General Social Survey, as information, counselling, respite, and financial compensation. Our study, however, also identified the need for social interaction as a prominent theme in the data.

Social isolation and loneliness were significant issues for the caregivers in this study. A previous study found that peer networks of four or five caregivers engaging in telephone conversations regularly can result in improved perceived social support and satisfaction (Goodman & Pynoos, 1990). There is little research in this area, however, and it is not clear whether telephone support by either professionals or peers can address the need for a social life. Comments from many caregivers in the current study indicated a desire to more regularly leave the caregiving setting for the purpose of social interaction. Thus, telephone support may not fully meet caregivers' needs for a social life. Other types of support, such as in-home respite offered by a trusted home-care worker in order to give family caregivers the opportunity to engage in social interaction, may be more likely to meet social support needs. Clearly, however, this type of support would require changes to the home-care system.

The caregivers in this study indicated that some informational and emotional support needs might be effectively met through a telephone support service. Colantonio et al. (1997) found that only a small percentage of their sample had ever used telephone support lines staffed by professionals (8.3%) or caregivers (2.3%). Similarly, few of the caregivers in the current study had ever used a telephone support service. Colantonio et al. also found that, of those not currently using a service, 57.1% would use one if provided by a professional and 57.3% if staffed by a caregiver. These numbers are consistent with the percentages of caregivers in our study who indicated they would use a service provided by a professional (71%) or a caregiver (59%). Colantonio et al. found that caregivers did not have strong preferences concerning professional- or peer-staffed services. While that result is generally consistent with ours, we did find that caregivers had a preference for professional support regarding issues such as medications, disease processes, and community services.

Our sample was broadly representative of caregivers of home-care users in terms of demographic characteristics. However, the sample included only English-speaking caregivers who provided care in non-palliative situations. Furthermore, the sample included only those who

had provided care for at least 6 months, and long-term caregivers are more likely to require support than those providing short-term care. Due to lack of information about refusers, we are unable to compare their characteristics with those of the participants. We do know, however, that the participants were not a biased group in terms of being satisfied with their home-care services; many openly expressed concerns about the home-care services they received (e.g., lack of consistency of staff).

Nurses can play a key role in providing professional telephone support to caregivers, in helping to establish and support caregiver-led telephone services, and in advocating for effective services to meet the broad range of expressed caregiver needs. The findings of this study have a number of implications for telephone support services. These services should offer practical assistance to caregivers, including information on topics such as care recipients' disease processes, medications, placement, respite, and links to resources and services. Information about services that might support the social lives of caregivers may be particularly important in view of the results of this study.

The participants in this study emphasized the need for a telephone support service that is available evenings and weekends. Further, telephone support should include both caregiver-initiated and provider-initiated services.

The providers of the telephone service should be knowledgeable about caregiving issues and community resources and should possess effective communication skills. The particular knowledge and skill set of nurses would be especially valuable in helping to train caregivers to provide emotional and informational support to peers.

Finally, there is a clear need for rigorous evaluation of different models (professionally led and peer-led) of telephone support for caregivers (Colantonio et al., 1997; Poole, 1997). Ideally, such evaluation would use a randomized controlled design in which the effects of telephone support are assessed separately from other interventions. The evaluation should include outcomes (e.g., health, caregiver burden, costs, satisfaction) as well as process (e.g., patterns of use of the service) (Wright, Bennet, & Gramling, 1998).

The results of this study reveal that some caregiver needs (e.g., physical support in providing care, more relief hours, financial compensation) cannot be met through a telephone support service. The literature supports the existence of such caregiver needs (Litwin & Lightman, 1996; National Advisory Council on Aging, 1990). In the case

of some of these expressed needs, services are available but caregivers either do not know of their existence or do not know how to access them. Thus, improved methods for referring caregivers to existing services should be an important goal for nurses and other home-care providers. In cases where such services do not exist, professionals, caregivers, and caregiver groups should work in partnership to advocate for their establishment (Anderson & Parent, 1999).

### Conclusions

This study identified the perceived needs of family caregivers of persons living with chronic illness and receiving home-care services. Caregivers identified the need for social interaction, information, emotional support, and instrumental support. Telephone support services have the potential to meet some caregiver needs for informational and emotional support, and possibly social support as well. A high percentage of caregivers indicated that they would use a telephone support service if available. Nurses can play a key role in providing telephone support services and advocating for other services to meet caregiver needs. They can also contribute to rigorous evaluation of telephone support services. Finally, it is vital that nurses work in partnership with caregivers to plan and provide caregiving services.

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# **Negotiating Care of Frail Elders: Relationships Between Community Nurses and Family Caregivers**

**Catherine Ward-Griffin**

Les changements récents dans les modèles de soins aux personnes âgées au Canada, dont le retrait des services officiels de soins à domicile et l'augmentation du recours aux fournisseurs de soins membres de la famille, exigent une analyse critique des relations entre les fournisseurs de soins officiels et non officiels. Le but de cette étude était de décrire et d'analyser la relation entre les infirmières et les membres féminins de la famille offrant des soins à domicile aux personnes âgées frêles. Recourant à une méthode ethnographique critique dans un cadre de travail socialiste et féministe, des entrevues en profondeur distinctes ont été menées auprès de 23 dyades d'infirmières et de fournisseuses de soins membres de la famille. L'analyse des transcriptions des entrevues et des notes prises sur le terrain a révélé que les relations se caractérisaient par l'incertitude et la tension. Alors qu'autant les infirmières que les membres de la famille fonctionnaient à l'intérieur des structures actuelles relatives aux soins à domicile tout en s'y opposant, les parties concernées étaient engagées dans un processus de négociation continu quant aux postulats culturels concernant la prestation de soins « privés » et « publiques ». Les résultats ont mis au jour les conséquences relativement à la pratique, à la formation et aux orientations de la profession infirmière.

Recent changes in patterns of care of the elderly in Canada, including the withdrawal of formal home-care services and increasing reliance on family caregivers, call for a critical analysis of the relationship between formal and informal caregivers. The purpose of this study was to describe and analyze the relationship between nurses and female family members caring for frail elders in the home. Using a critical ethnographic method in a socialist-feminist framework, separate in-depth interviews were conducted with 23 nurse-family caregiver dyads. Analysis of interview transcripts and fieldnotes revealed that relationships were characterized by uncertainty and tension. While both nurses and family caregivers functioned within and resisted current home-care arrangements, they engaged in an ongoing process of negotiating cultural assumptions about "private" and "public" caregiving. The findings point to implications for nursing practice, education, and policy.

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## **Introduction**

As a result of the combined effects of an aging population, reduced health-care services, and a belief that home care is preferable to institutional care, families continue to experience pressure to assume more caregiving responsibility for the frail elderly. Families and friends have always been the greatest source of in-home support for the elderly in Canada, as high as 90% in the province of Ontario (Ministry of Health, 1993). The movement towards a home-care approach is also driven by the assumption that home care is more cost-effective than institutional care. However, there is considerable evidence that female family members, who assume the vast majority of informal caregiving responsibilities, bear tremendous physical, emotional, and economic costs (Abel, 1990; Baines, Evans, & Neysmith, 1991). Policy-makers rarely take these into account when making decisions about the cost of delivering home-care services.

Another cost-cutting strategy used within home-care systems is the expectation that families will assume an active role in elder care. In Ontario, family involvement is a condition of receiving home-care services through the Community Care Access Centres. Although the relationship between professional and family home-care providers revolves around a shared concern with meeting the health-care needs of elders, family caregivers are increasingly expected to perform complex technical tasks previously carried out by professionals (Glazer, 1990; Guberman & Maheu, in press). Thus, community nurses are expected, more than ever before, to teach, delegate, assign, or supervise the care provided by family members. Since many family caregivers gradually develop a skill repertoire and a store of knowledge concerning the elder's needs, it is inevitable that complex negotiations related to authority, accountability, and values will arise between the two caregiver groups (McKeever, 1994), and that these negotiations will be complicated by ambiguity about role expectations and status.

Although much has been written about how informal and formal caregivers should relate to one another, there has been little empirical analysis of the relationship. This paper aims to provide a critical analysis of the nurse-family relationship in home care. Findings from a qualitative study illustrate how care of the elderly is negotiated between informal and formal caregivers. They illuminate, in particular, how nurses and families reaffirm, accommodate, and challenge existing boundaries of caregiving; how nurse-family caregiver relationships are formed and negotiated within the home-care system; and how cultural ideologies shape the negotiations. The paper concludes with practice, education, and policy implications for nursing.

### **Literature Review**

The literature addressing the relationship between health professionals and families in home care is limited. Most studies that have examined caregiving in the home have focused on family caregivers. Family caregivers of the elderly have been asked about their own caring work and its effect on their lives (Abel, 1990; Dwyer & Seccombe, 1991; Keefe, 1990; Navon & Weinblatt, 1996; Pohl, Collins, & Given, 1995), the caring work of the professionals with whom they interact (Dansky, Brannon, & Wangness, 1994; Pringle, 1982), and their relationships with those professionals (Hasselkus, 1988, 1992; Keady & Nolan, 1995; Nolan & Grant, 1989; Ong, 1990; Pohl et al.). Limited attention has been given to formal caregiving in the home, and those studies that have included this aspect have focused on personal-support workers rather than health professionals. Formal caregivers of the elderly in the home have been asked about their own caring work (Aronson & Neysmith, 1996; Bartoldus, Gillery, & Sturges, 1989; Martin Matthews, 1992; Neysmith & Nichols, 1994; Pringle; Qureshi, 1990), the caring work of the family (Kaye, 1985), and their relationship with the family caregiver (Aronson & Neysmith; Kaye). Both professional and family caregivers have been found to value individualized affective care accompanied by good instrumental care. However, the perceptions of the two groups tend to differ with respect to the particular types of care that should be provided by each.

A few researchers have actively sought to gain insight into how family caregivers and health professionals work together to provide elder care in diverse settings (Fischer & Eustis, 1994; Rubin & Shuttlesworth, 1983; Schwartz & Vogel, 1990) and how that relationship changes over time (Clark, Corcoran, & Gitlin, 1994; Keady & Nolan, 1995). Most of the existing work on the relationship suggests that conflicts may arise when health professionals fail to recognize a family caregiver's expertise (Duncan & Morgan, 1994; Hasselkus, 1988); when roles overlap (Cott, 1991; Kaye, 1985; Schwartz & Vogel); when roles are rigidly defined (Bowers, 1988; Duncan & Morgan); or when there are discrepancies in role expectations, treatment goals, or values (Hasselkus, 1988; Nolan & Grant, 1989; Schwartz & Vogel). Other work describes the relationship as an alliance based on communication and mutual respect (Fischer & Eustis). Few studies, however, have specifically asked why health professionals and family caregivers tend to operate from different assumptions and value systems or have conflicting role expectations. Although many researchers cite the need for collaboration between health professionals and families, few raise the

issue of the power differential between the two groups, or address the difficulties that this power differential can introduce into the relationship.

Less clear and less documented still is the specific relationship between nurses and family members who provide care to frail elders in the home. Although the aforementioned studies emphasize the importance of relationship-building on the part of health professionals and family caregivers, there has been little systematic analysis of how nurses and family caregivers negotiate the care of the elderly and the specific negotiation strategies they use. Moreover, the social context and the consequences of this negotiation process are rarely examined.

### **Theoretical Perspective**

The current study was informed by a socialist-feminist perspective of caring (Fisher & Tronto, 1990; Ungerson, 1990) supplemented by Twigg and Atkin's (1994) typology of family caregivers and Gerson and Peiss's (1985) activist view of negotiation. A socialist-feminist inquiry is particularly useful in conceptualizing caregiving because of two distinctive features: caring work occurs in both the private sphere and the public sphere, which are interwoven; and caregivers' everyday experiences are inextricably connected to the larger political, social, and economic environment. As with other critical theoretical perspectives, a basic principle of the socialist-feminist approach is that caring work cannot be understood in isolation from the social, political, and economic conditions in which it takes place. Research on health-care relationships has tended to focus on the micro process of interaction without taking account of the macro-level social and economic forces in the marketplace and the home. In other words, women's caring work not only is structured by economic relations, but also maintains and reproduces these relations. It is also important that macro-level structures, such as formal home-care policies and administrative rules, be understood in terms of their relationship to the everyday lives of caregivers. The socialist-feminist perspective and its utility have been more fully described elsewhere (Ward-Griffin & Marshall, 2001).

Since Twigg and Atkin's (1994) conceptual model focuses on the perceptions and roles of professionals in responding to family caregivers, it was a useful template for examining the ongoing negotiations between formal and informal caregivers. Twigg and Atkin suggest that the definition of the situation, the conceptualization of need, and the acceptability of the care provided are all subject to negotiation between the professional and the family caregiver. Implicit in this process is a

recognition that both parties are active participants, asking or demanding that resources be shared or reallocated (Gerson & Peiss, 1985). This perspective of negotiation reflects an activist view of human agency: humans are creative and reflexive, capable of adjusting their actions to fit the situation (Giddens, 1993). Supplementing an activist view of agency with a socialist-feminist perspective of caregiving will help to illuminate how caregivers produce and reproduce, but also resist and undermine, current economic and ideological structures. Thus, there is a dialectical relationship between individual meanings and the wider social organization, which is mediated through nurse-family caregiver negotiations.

## **Method**

### *Purpose and Design*

The underlying assumptions of feminist methodologies situate them within a critical approach to research (Neysmith, 1995). The purpose of this study was to describe and explore, using a critical ethnographic approach, the relationship between nurses and female family members caring for an elder in the home. Of particular interest were the forms that this relationship takes and the strategies, conditions, and consequences of the negotiation process. Critical ethnography was chosen because research, in this approach, makes explicit what is implicit in a culture (Thomas, 1993). While conventional ethnography treats the descriptions of cultural traditions as complete in and of themselves, critical ethnography is recognized as "having conscious political intentions that are oriented toward emancipatory and demographic goals" (Quantz, 1992, p. 448). Thus, adopting a critical stance towards assumptions of formal and informal caregiving provides an opportunity to engage in positive social change.

### *Sample*

Using a two-phase sampling frame, registered nurses and family caregivers of elderly individuals were recruited over a 5-month period (August–December 1996). Inclusion criteria were: participants had to speak and understand English; participants had to have interacted with one another on four or more occasions; family caregivers had to have provided regular care (at least weekly) to a frail family member 65 years of age or older; and nurses had to be currently employed full-time or part-time at one of the three non-profit community nursing agencies in southwestern Ontario. All registered nurses ( $N = 127$ ) were sent a

letter inviting them to participate; 43 responses were received (34% response rate). Nurses who met the eligibility criteria were asked to approach family caregivers who met the eligibility criteria to determine their interest. Family caregiving was defined according to Hooyman and Gonyea's (1995) definition, as services provided for the well-being of older individuals who, because of physical or mental disabilities, cannot perform such tasks themselves. This sampling frame may have introduced biases in that some nurses may have avoided "difficult" family caregivers or caregivers who would find an hour-long interview too tiring. However, it was a condition put forth by the participating community nursing agencies, suggesting that this approach may minimize potential coercion by the researcher and safeguard confidentiality of the family.

Purposive sampling led to the selection of 23 nurse-family caregiver dyads (Patton, 1990). The dyads had known one another from 3 months to 14 years, with a mean of just under 3 years. Most saw each other weekly. The average age of the nurses was 47 years. All but one were female. The majority were born in Canada (67%), spoke English as their first language (93%), held a nursing diploma and/or a specialty certificate (53%), and had been practising community nursing 11 or more years (53%). The family caregivers ranged in age from 33 to 82 years; most were over 60 years. None of the family caregivers were employed full-time but three were employed part-time. All were female. The majority were born in Canada (65%) and provided care to their husband (70%) who had a chronic illness (87%). The elders ranged in age from 65 to 99 years with a mean age of 78.9 years. As will be discussed below, virtually all of the elders required continuous, intensively demanding daily care. Family caregivers provided higher levels of care than the general estimate of 5 hours per week (Arber & Ginn, 1990). Due to the complexity of care required by the elder, the majority of nurses made weekly visits (57%).

### *Data Collection and Analysis*

The major sources of data for the study were 38 in-depth interviews and corresponding fieldnotes. Demographic data were collected from the participants at the end of each interview and analyzed using descriptive statistics. Separate in-depth focused interviews (Merton, Fiske, & Kendall, 1990) were scheduled at a mutually convenient time and place for the nurse and family caregiver. Using a semi-structured interview guide informed by socialist feminist assumptions of caring work, participants were encouraged to talk about the paid and unpaid

care provided to the elder, the nurse-family negotiations concerning their caregiving responsibilities, and the conditions (social, political, and economic) and consequences of these negotiations. In response to open-ended questions (e.g., Can you tell me what your experiences have been in caring for X?), most participants discussed their caring work and relationships without further prompting. The interviews averaged 75 minutes. All were audiotaped. Approximately half of the interviews with nurses were conducted in their homes and half in their offices. Interviews with the family caregivers were conducted in their homes; all but one of the caregivers lived with the elder requiring care. Interviews were carried out until an adequate amount of data had been collected. As recommended by Morse (1994), it was anticipated that approximately 30 interviews would be adequate to obtain comprehensive descriptions sufficient for ethnographic research, but additional participants were added to ensure adequacy. Adequacy is attained when enough data are collected to provide a full and rich description of the phenomena — that is, when saturation occurs (no new data will emerge by conducting further interviews) (Morse & Field, 1995).

As recommended by Miles and Huberman (1994), a provisional list of codes was drawn up prior to interviewing based on the study's theoretical framework and research questions. These preliminary coding categories, related to caregiving and informal-formal relationships, were applied to the first set of transcripts and fieldnotes, then examined for fit. This method, situated between the a priori and inductive approaches to coding, helped create codes inductively nested in each general category. Early analysis focused on key phrases and themes that emerged from the data. As common themes emerged progressively, new codes were added, producing numerous and varied codes (Lofland & Lofland, 1995). These codes were inserted into the text by hand and then entered onto NUD\*IST (Richards & Richards, 1994). The process of sorting and resorting data to locate patterns between coding categories was facilitated by the software program. (The author can be contacted for details about the techniques used to ensure credibility of the findings.)

## **Results**

Using the coding method described above, an initial index system of 60 codes emerged. Codes were discarded or refined if they were not supported empirically by the data or were overly abstract. The codes were frequently regrouped or revised, resulting in a final total of 35. The index system that emerged from the coded data captured the general

categories of caring work (e.g., physical, emotional, intellectual); nurse-family caregiver relationships (e.g., as friends/family, as co-workers); types of negotiation strategies (e.g., refusing to care, delegating care); and conditions (e.g., age of caregiver, agency policies) and consequences of caregiving (e.g., quality of life for elder, for caregiver). This index system was consistent with and reflected the theoretical framework that guided the study. In particular, the socialist-feminist principle that the organization of caring work is part of the larger social, political, and economic environment was strongly supported by the data.

The findings revealed that relationships between community nurses and family caregivers are complex, multifaceted, and dynamic. Both groups performed all facets of caregiving — physical, intellectual, and emotional — but to varying degrees and for different reasons. Nurse-family caregiver relationships that evolved through caring for an elder at home were of four types: nurse-helper, co-worker, manager-worker, and nurse-patient. Finally, while both nurses and family caregivers collaborated in and resisted existing caring arrangements, they engaged in a process of negotiating cultural assumptions of “private” and “public” caring. It became evident that the opportunities for negotiation were more limited for family caregivers than for nurses, reflecting the powerlessness of an individual whose caring work is not publicly visible. This position of invisibility supports prevailing conservative political ideologies. Indeed, nurses relied on ideologies of “familism,” “fiscal restraint,” and “choice” to transfer caring work between the informal and formal caring systems. Ideologic work by nurses constituted the most powerful, but covert, means of controlling the caring work of family caregivers.

### *Boundaries of Care*

Family caregiving was described by both groups in terms of continuous, demanding, daily care. It consisted of personal care, monitoring, and emotional support. In addition, every family caregiver performed a number of complex technical procedures, such as wound dressing, tracheotomy suctioning, and administration of medication. General perceptions about family caring were similar for nurses and family caregivers, with two notable, interrelated differences. First, nurses described family caregiving mostly in terms of “dirty” hands-on care — unskilled labour that can be easily learned. They rarely acknowledged the importance of emotional and intellectual informal care to the same extent as the family caregivers did. Second, even though it is clear that a family caregiver gradually becomes expert on the elder’s health-care needs,

nurses tended to give less importance to the caregiver's level of knowledge and competence.

Perhaps the failure to recognize the family caregiver's knowledge stems from the importance attributed to the nurse's role as monitor. Both groups tended to describe nursing care in terms of periodic assessment and supervision. Caregivers explained that nurses provided this type of care because of their superior knowledge and expertise: "I couldn't fulfil what Diane does. Her knowledge. Her expertise. Her experience. She uses all that. What I do is provide meals, get the groceries. I have to run the house as well... I don't think we overlap at all. I don't think she could do what I do, because mine is so menial and hers is professional." When nurses provided hands-on care — usually temporarily — it was described as a "technique" or means to an end such as "building trust," "assessing the elder's condition," or "providing relief for the family." Moreover, unlike family caregivers, nurses had choices concerning whether and when to provide hands-on care. Another major difference in perceptions about nurses' caring work concerned the emotional support they provided to both the elder and the caregiver. While nurses saw this as a key component of their role, many family caregivers perceived it as personalized attention and extra effort "beyond the call of duty." Thus, there appears to be a clear division of labour between nurses and family caregivers not only in terms of specific functions, but also in terms of manual and intellectual work.

On closer examination, however, it was apparent that nurses and family caregivers crossed the boundaries separating "manual, unskilled" from "intellectual, skilled" work. Although both groups sought to maintain distinct boundaries between their caring work, the findings revealed that family caregivers gradually provided complex, technical tasks typically seen as professional nursing care. Similarly, if family caregivers were unable to provide hands-on care, particularly when they were ill or too tired or when the elder's condition worsened, some nurses temporarily assumed a greater portion of "unskilled" responsibilities, frequently working longer hours or without pay. It is to these relationships between nurses and family caregivers that we now turn.

### *Relationships Between Nurses and Family Caregivers*

The nurse-family caregiver relationship shifted and oscillated among four interrelated types: (1) nurse-helper, (2) worker-worker, (3) manager-worker, and (4) nurse-patient. A detailed description of these relation-

ships has been published elsewhere (Ward-Griffin, 1999; Ward-Griffin & McKeever, 2000).

In the *nurse-helper* relationship, the boundaries were relatively unambiguous. The nurse took the time to provide and coordinate the majority of care, while the family caregiver assumed a supportive role. At times, family caregivers actively sought out opportunities to be involved, but although nurses acknowledged and supported the involvement of family in the elder's care, they did not transfer their nursing work to the caregiver. Nurses within this relationship tended to assume more responsibilities than assigned by the agency, and resisted agency policies and directives to relinquish this care. Both parties recognized and valued the contributions of the other. While most nurses and family caregivers stated that this was the type of relationship they had had at the beginning of the elder's illness, it was the least common type in this study ( $n = 3$ ).

Although only a few dyads currently functioned in a *co-worker* relationship, most had done so in the past. In contrast to the original nurse-family caregiver relationship, this one was filled with tension, conflicts, and ambiguities. Based on the notion of teamwork, nurses attempted to collaborate with family caregivers in a way that recognized their expertise yet co-opted them. Negotiations focused on family caregivers' growing competence and acquisition of caregiving skills usually associated with nursing. Many nurses downplayed the complexity of these skills while at the same time seeking to gain the family caregiver's trust in order to delegate their nursing work. If necessary, nurses would be careful to give the caregiver time to "get used to the idea" before transferring the work. Although many family caregivers complained of feeling uneasy, overwhelmed, or angry because the task appeared too difficult, they usually agreed, deferring to the nurse's professional opinion and experience. Consequently, nurses were able to gradually reduce the frequency of their visits as the family caregivers were co-opted into becoming informal members of the health-care team.

The vast majority of the dyads ( $n = 16$ ) functioned in the third type of relationship, *manager-worker*. As nurses gradually transferred their actual caring work to the family caregiver, their supervisory tasks — such as monitoring the "coping skills" of the caregiver — increased in importance. These nurses acted primarily as "resource persons," providing information or emotional support. They saw the elder and family caregiver infrequently and sporadically, using as justification the fact that the elder's condition was "stable" and the caregiver was "competent." Although family caregivers had generally accepted increases

in their caring work in terms of complexity and time, many were confused and sad that the nurse had reduced her involvement. A few resisted the nurse's attempts to set limits, but with minimal success.

The fourth type of relationship, *nurse-patient*, occurred almost as frequently as the manager-worker relationship, and as a consequence of it. As a result of their relentless caregiving demands, family caregivers became the nurses' patients. Nurses were faced with contradictory expectations: they were expected to relate to the family caregiver both as worker and as patient/client. Many family caregivers characterized their situation as "living on the edge" or "not having a life of my own." While nurses expressed concern for the health and well-being of the family caregiver in these crisis situations, they claimed that they were doing their best given the current fiscal reality of the home-care system. Only rarely, however, would nurses consider increasing their own or other formal caregiving efforts to ease the family caregiver's workload. Consequently, for many family caregivers the demands of caring induced illness, because they did not have the same opportunity as nurses to delegate their work to others.

Thus, the results show that relationships between nurses and family caregivers in home care tend to be ambiguous and characterized by tension. The findings also suggest that ideologies constitute the most powerful, though covert, influence in nurse-family caregiver negotiations.

### *Ideologies and Nurse-Family Caregiver Negotiations*

An ideology is a set of beliefs and attitudes of a group about a social reality, as well as the practices and motives that embody these beliefs and attitudes (Geuss, 1981/87). Two interrelated ideologies shaped the negotiations between nurses and family caregivers: fiscal constraint and familism. Nurses described constant pressure from management to "cut costs" by finding the least expensive home-care service or reducing the frequency of their home visits. This relentless drive to reduce or eliminate induced a sense of powerlessness in many nurses. Due to heavy workloads, they felt they had little choice but to comply. Moreover, as guardians of the public purse they believed they had a role to play in saving money within the health-care system. Their methods for doing so included: transferring caring work to family caregivers and/or "less skilled" home-care workers; restricting "complete" home-care services to family caregivers of terminally ill elders, who were considered in greater need than family caregivers of chronically ill elders; encouraging family caregivers to pay for private home-care services; and reallo-

cating, in an "equitable" manner, home-care supplies and services from those who did not need it to those who did. These cost-cutting strategies required nurses and family caregivers to continually negotiate the boundaries between skilled and unskilled labour and between public and private costs.

Coupled with the ideology of fiscal restraint, familism played a central role in the negotiations between nurses and family caregivers. Familism — the idealization of what a family should embody — is rooted in the principle of "private" responsibility, which emphasizes self-reliance, privacy of the family home, and freedom from intrusion (Hooyman & Gonyea, 1995). Virtually all family caregivers expressed a duty and obligation to assume the role of caregiver. Caring was regarded as "natural" for women and as a "family duty," particularly for older spousal caregivers. Familism, with its prescriptive assumptions about the "natural" and "right" position of women (and men) within marriage, shaped their experiences and their expectations about the provision of care.

Similarly, nurses' opinions about the degree to which family members "should" care for their elders were shaped by personal values and assumptions based on traditional gender roles, family relations, and the caregiver's age. Nurses openly encouraged younger women to "lead their own lives" — to consider placing their grandmother in an institution, for example. In the case of older women, in contrast, nurses placed a higher value on "love and family care." They particularly admired older family caregivers who were "devoted" and "dedicated," and frequently told them so. Moreover, most nurses placed the onus for caring on the family, viewing home-care services as playing a secondary role. They saw family care provided in the home as superior to institutional care. Interestingly, the majority of nurses assumed that family caregivers were free to choose alternative forms of care, even though they acknowledged that such options were often limited or inappropriate. Although family caregivers rarely questioned the naturalness of family care, they differed from the nurses in their opinions about it as a "choice"; the lack of options led many family caregivers to believe they had no choice but to provide the bulk of care.

Thus, ideologies that view home care as better and more cost-effective than institutional care, and that view women as natural caregivers, sustain the current system of home care and preclude caregiving alternatives both within and outside of the home-care system. Ideologies are invoked by nurses, as guardians of the public purse, in the transfer of economic responsibility for elder care from the public to the private

domain. The power of these ideologies is reflected in the compliant behaviour of family caregivers in assuming the bulk of *work* in elder care and in eventually also assuming the greater portion of *responsibility* for elder care.

### **Implications for Nursing**

The findings of this study provide evidence that relationships between nurses and family caregivers in the home-care system present a particular challenge. They tend to be characterized by uncertainty, tension, and power struggles. While both nurses and family caregivers feel it is important to develop collaborative relationships, they must constantly negotiate care in an emotionally charged "intermediate" domain. Located between the public world of paid work and the private world of the family, Stacey and Davis's so-called intermediate domain (cited in Mayall, 1993) is a contested arena. Negotiation between nurses and family caregivers is impeded by many factors: blurred boundaries between skilled and unskilled caregiving; unequal division of formal and informal care; powerlessness on the part of both nurses and family caregivers; and acceptance of the notion that caregiving is women's work. In the process, alliances of nurses and family caregivers are formed under the guise of partnership, only to be severed and rebuilt to conform with home-care policies and priorities. The questions that this study raises about the relationships between nurses and families caring for frail elders at home have implications for nursing practice, education, and policy.

Previously published discussions of the current findings (Ward-Griffin, 1999; Ward-Griffin & McKeever, 2000) include implications for nursing practice. Briefly, nurses need to: (1) evaluate the negative consequences of transferring care from paid caregivers to the family, (2) acknowledge an ethical responsibility to support family caregivers by providing adequate resources, and (3) ensure that women are not coerced into assuming their "natural" role as family caregivers. In short, the time has come for nurses to advocate for and with family caregivers, as a first step in the development of a genuine partnership.

Given these implications for practice, all health disciplines may need to make curricular changes, in order to prepare practitioners in the building of collaborative relationships with family caregivers. Educators are challenged to adopt creative teaching strategies with the ultimate goal of enabling future practitioners to effect social change — to reform rather than to reproduce gendered power relations (Ward-Griffin & Ploeg, 1997). Nurse educators may have to examine their

current teaching methods and opt for a more collaborative learning approach (Boughn & Wang, 1994). What is needed is an environment that fosters shared leadership in the classroom and in clinical settings, with students learning to identify areas that require social change, to examine their role in effecting change, and to identify sources of support for social change (e.g., the Ontario Nurses Association). Nursing students must be given opportunities to examine the power dimensions of their professional relationships with families and to identify collaborative political strategies such as coalition-building. Nursing faculty must critically examine the training and indoctrination of students into the profession to determine whether they promote the ideologies of familism and essentialism (i.e., woman as nurturer). All of these strategies might equip future practitioners to address some of the inequities in the home-care system.

Partnerships with family caregivers are important in the political arena as well. The future well-being of family caregivers depends, in part, on the development of sound, socially relevant policies to correct inequities in the home-care system. If this goal is to be met, partnerships will have to be fostered among all caregivers, both formal and informal. Individual health professionals, and their provincial and national organizations, will have to join in the efforts of other caregivers. The recent establishment of the Canadian Coalition of Caregivers represents an opportunity for nurses and family caregivers, along with other key stakeholders, to jointly identify and prioritize caregiving issues. This multi-sectoral coalition is an important first step in recognizing and addressing the powerlessness common to all caregivers, by working together in equal partnership with community members, professionals, volunteers, and care recipients. By lobbying policy-makers and key decision-makers at the provincial and national level they can contribute to policy change and the development of a new paradigm for caregiving in Canada. Significant changes must be made not only in the workplace but also in government policies that constrain both families and health professionals in their caregiving efforts.

Finally, the findings of this study are consistent with those of Hooyman and Gonyea (1995), that we need to challenge the pervasive ideologies of familism that undergird implicit and explicit policies and to envision alternative models of care. For instance, the community-oriented approach suggested by various authors (Guberman & Maheu, in press; Neysmith, 1991) situates the ultimate responsibility for caregiving with the community as a whole. This could be the new paradigm for caregiving in Canada. In the social-care model, care of the elderly is

seen not as a "problem" for individual families to resolve but as a social responsibility warranting a collective response by all concerned stakeholders. The central tenets of the social-care model are: genuine choice for individuals about whether to assume family caregiving; access to a guaranteed minimum level of services for all disabled persons; and caregiver/care recipient participation in policy development at all levels of the health-care system (Guberman & Maheu). In the social-care model, nurses and family caregivers enter into a relationship that is unambiguous, for the purpose of building a genuine, equal partnership.

In conclusion, the results of this study demonstrate that the responsibility for elder care is unequally distributed between nurses and family caregivers. Of particular concern is the evidence that current home-care practices and policies create or intensify problems for family caregivers. The ideologies that inform both nurses and family caregivers serve to exploit female family members by coercing them into taking on the bulk of care. As governments seek more and more ways to cut health-care costs, it is reasonable to predict that in the future families will experience even greater difficulties in caring for the frail elderly. These inequities will not necessarily be sustained, however, if nurses take the opportunity to seriously look at what they do and the outcomes they want to achieve (Fisher, 1990). Policies that constrain and work to the detriment of both formal and informal caregivers must be changed. Nurses must join other professional and lay organizations in lobbying for radical alterations to structures and ideas that perpetuate the unequal division of labour between private and public caregiving. Only when policies reflect the principles of primary health care, including equity, empowerment, and multi-sectoral collaboration, will there be a genuine partnership between nurses and families in home care.

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## *Designer's Corner*

### **Centring the Home in Research**

**Isabel Dyck**

The Oxford dictionary includes in its definitions of the home (a) "the place where one lives; the fixed residence of a family or household," and (b) "a dwelling-house." This core space of everyday life, embedded in a legacy of ideas of the home as a haven of domesticity, separate from the harshness of the public world of paid work, is, however, being shown to be a far more complex concept and reality than a simple dictionary definition suggests.

Geographers, particularly those working from a feminist perspective, have challenged accepted notions of the distinction between public and private, of "family home," and of the home as necessarily a safe space for women and children. An array of findings demonstrate, for example, a multiplicity of family forms and living arrangements accompanying demographic and social change, and a blurring of the boundaries of home and work as women's engagement in different forms of domestic and paid work in their own or others' homes is recognized. Furthermore, the influence of normative heterosexuality and notions of the private, nuclear family are being shown to marginalize certain family forms, such as the lone parent or the gay/lesbian household, and to shield domestic violence (see Dowling & Pratt, 1993, for an overview of geographical studies).<sup>1</sup> In sum, "the family home" is a complex spatial and social institutional arrangement that needs considerable unravelling if it is to be fully understood. Certainly, the diversity of families, household arrangements, meanings of home, locations, and spatial arrangements of homes suggests that integrating the home into research can contribute to our understanding of the connections among everyday lives, health, and the management of illness and disability.

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<sup>1</sup> My work includes investigation of the home as a site where disability and chronic illness are negotiated by women with multiple sclerosis (Dyck, 1995, 1998) and where domestic labour and paid labour are integrated by suburban mothers of young children (Dyck, 1989, 1990).

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This is particularly so given trends in the health-care system towards community care.

Designing research centred on the home entails thinking about the links between chosen field methods and conceptualizations of the home. It also entails thinking about the home as a field site where the complexity of research relations plays out. Let us think first of the home as a core site in the sociospatial arrangement of everyday life, which may encompass multiple activities and meanings. To begin with, and in light of existing research, this means approaching the home as both a material and a "discursive" site. As a material site its spatial arrangements, location (neighbourhood), amenities and furnishings, and running costs are all relevant. Considering it as a discursive site means taking into account how dominant social discourses — for example, on gender, ability/disability, health/illness, and sexuality — inform social and health policy and also inform and are negotiated in the ways a home is used and the meanings about it created. Yet materiality and discourse are neither separate nor fixed, so that while normative ideas shape how the home is used and arranged, specific uses and arrangements may "rework" dominant ideas. For instance, a woman with multiple sclerosis who can no longer function in a city workplace and thus restructures her home environment can renegotiate her identity as "able" and redefine her home as a workplace outside the confines of commonly understood norms. Similarly, the entry of care services into the home both challenges the notion of the home as a private space and redefines it as a workplace (of the paid caregivers).

In practical terms, we need methods that focus on observation and/or accounts of the home as both a material and a discursive site. A particular dimension of the home may be foregrounded, however, depending on the research question and the scope of the research. There may be a focus on policy, for example, or on the experiences of various users of the home, or there may be a comprehensive view that aims to bring in several dimensions of the home. Narrative accounts of everyday life through in-depth semi-structured interviews can reveal many uses and meanings of the home and many aspects of its relationship to external spaces. The arrangement and uses of home can also be observed and recorded, through mapping, videotaping, and other observational techniques that offer a nuanced view of the materiality of home space.<sup>2</sup> The people, spaces, and temporal rhythms of daily

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<sup>2</sup> An interdisciplinary project headed by Patricia McKeever, Co-director, Home and Community Care Evaluation and Research Centre, Faculty of Nursing, University of Toronto, is currently investigating the home as a site of care using a variety of interview and observational methods.

routine can enable the researcher to reveal the significance and meanings of the home to those living in it, as well as how these are shaped by other spaces and relationships not visible in a tangible way in the home. For example, the meanings and uses of home for a man with HIV/AIDS may change with his decreasing ability to use neighbourhood spaces, but are also framed by social policy, the power of biomedicine to label him as a palliative-care patient, and local friendships and resources (Dyck & O'Brien, 2001).

Another aspect of the research equation is the home as field site. In conducting interviews or other field work in the home, we blur the boundaries of public and private by entering the participant's home as a researcher backed by the authority of a university or granting agency. And we do not leave the site undisturbed. The questions we ask and the information we may dispense may result in participants renegotiating how they see themselves or possessing the knowledge to access resources. In research that is potentially intrusive the researcher must be careful to follow ethical procedures. The reflexivity common to qualitative inquiry is a further important ingredient of the research process. It helps us to understand how the home as field site, in both its materiality and its meaning, mediates research relations and the knowledge constructed.

Centring the home in research offers an exciting opportunity to enrich analysis by investigating the role of space in everyday experiences and the ways in which socio-economic and political processes condition these experiences. A focus on the home may also suggest taking a different perspective on a particular topic, such as domestic violence, parenting a disabled child, or living with a psychiatric illness. In short, taking the home into account opens up ways of looking at health-related issues that do not isolate the participants' experiences from the material conditions of their everyday life and the relations and discourses that shape them.

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## Happenings

### **Making Evidence-Based Practice a Reality: The National Center for Children, Families and Communities**

**Ruth A. O'Brien and Patricia Moritz**

As the quantity and quality of nursing research have evolved, the discipline has been urging staff nurses to systematically apply research findings in their practice. Larger health-care organizations have created positions for nurse researchers in order to provide the expertise necessary to guide clinicians in evaluating the scientific merit and practical value of published studies, and to develop studies that address important clinical issues. While these efforts have been met with varying degrees of success, the challenge to build evidence-based practice remains a daunting one.

In particular, the use of complex, well-tested experimental nursing interventions in clinical practice can be problematic unless the dissemination process is carefully planned and monitored. The National Center for Children, Families and Communities, an interdisciplinary body of the schools of nursing and medicine at the University of Colorado Health Sciences Center, is devoted to research, development, and replication of programs that enhance the lives of children and families in the context of the communities in which they live. The first major initiative undertaken by the Center is replication of the Nurse-Family Partnership program.

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### **The Nurse-Family Partnership**

The Nurse-Family Partnership (NFP) is a highly acclaimed, well-tested model designed to enhance the health and social functioning of low-income first-time mothers and their babies. Current theory suggests that intervention during the prenatal and early childhood periods is critical for achieving long-term results in the life course of at-risk families. Starting in pregnancy, nurse home visitors address women's health behaviours related to substance abuse (tobacco, drugs, alcohol), nutrition, vaginal and urinary tract infections, significant risk factors for preterm delivery, low birth weight, and infant neurodevelopmental impairment. After delivery, the emphasis is on optimizing the quality of family caregiving for infants and toddlers, in order to prevent child maltreatment and injuries (the leading cause of mortality among children aged 1 to 14 years). The program also focuses on preventing unintended subsequent pregnancies, school dropout, failure to find work, and welfare dependence — factors that conspire to enmesh families in poverty and increase the likelihood of poor subsequent pregnancies and sub-optimal child care. In order to maximize outcomes, nurse home visitors seek to improve environmental conditions by enhancing informal support for families and linking families with health and human services when needed.

Evidence for the effectiveness of the program has been established through three randomized clinical trials (Olds et al., 1997; Olds, Henderson, Cole, et al., 1998; Olds, Henderson, Kitzman, et al., 1998). Compared to counterparts in the control group, key findings for the nurse-visited women and their children include:

- 25% reduction in cigarette smoking during pregnancy among women who smoked at program entry
- 56% fewer hospital emergency room visits for injuries
- 79% reduction in rates of child maltreatment among at-risk families from birth through the child's 15th year
- 43% reduction in subsequent pregnancy among low-income unmarried women by the first child's 4th birthday and 31% reduction through age 15, with a 2-year increase in the interval between the birth of the first child and the second pregnancy
- 83% increase in the rates of labour-force participation by the first child's 4th birthday
- 30% reduction in welfare utilization among low-income unmarried women by the first child's 15th birthday

- 69% fewer arrests among low-income unmarried women over the 15 years following enrolment in the program
- 54% fewer arrests and 69% fewer convictions among the 15-year-old children of mothers enrolled in the program.

### **Evolution of the Center**

In 1995, David Olds, Principal Investigator for the trials, and Ruth O'Brien, Co-Principal Investigator, accepted an invitation from the US Department of Justice to disseminate the program to six of its high-crime "Weed and Seed" communities in Florida, Missouri, Oklahoma, and California. Concomitantly, pilot programs were established in Ohio and Wyoming through fee-for-service contracts. As evidence from the trials came to the attention of policy-makers, requests for assistance in replicating the model were received. In early 1997, four additional pilot sites were established in Oklahoma through funding from the state legislature, and by 1998 the program had rapidly expanded statewide. Patricia Moritz serves as Principal Investigator for evaluation of the replication in Oklahoma. In 1998–99, with a grant from the US Department of Health and Human Services, further small-scale dissemination of the model was undertaken with a limited number of communities.

Through our early efforts with replication of the NFP, we recognized the importance of developing an infrastructure that would enable us to work with communities to develop the NFP and sustain it over time. Thus, in collaboration with colleagues at Replication and Program Strategies, Inc. (a not-for-profit organization based in Philadelphia devoted to the wide adoption of evidence-based programs), who had worked with us in our early dissemination efforts, we sought funding from the Robert Wood Johnson Foundation to establish the National Center for Children, Families and Communities.

### **Core Services of the Center**

The Center was officially established in November 1999. Currently its operating costs are covered through grants from the Robert Wood Johnson Foundation, the David and Lucille Packard Foundation, and the Doris Duke Foundation, and through contractual fees from program sites. A business plan is being developed to move the Center towards full self-sustainability.

As noted, the NFP is the first program replication undertaken by the Center. As of July 2001, it has been implemented statewide in Wyoming and Oklahoma and 102 cities or counties in 22 other states. Our ultimate goal is to make the NFP available to every low-income first-time mother in the United States who wishes to participate. If developed on this scale, the program will serve approximately 180,000 pregnant women and their families each year. Based on our current capacity for national support, we estimate that it will take 20 years to develop the NFP on this scale, with the assurance that each site is of sufficient quality to produce results comparable to those achieved in the randomized trials.

The Center has developed a set of core services designed to enable local communities to develop and sustain the NFP. These are: (1) site development and application processes for public health/community agencies interested in replicating the program, (2) design and use of visit-by-visit practice guidelines based on trial protocols with client individualization as needed, (3) training of public health nurses and their supervisors in implementing the intervention, (4) development of clinical data forms and a computerized information system to monitor fidelity of implementation, and (5) agency access to and guidance in use of evaluation data for quality assurance. A brief description of these core services follows.

*Site development specialists* respond to all requests for information about the NFP and queries concerning the process for being accepted as a participant in our dissemination efforts. They work closely with local community and agency leaders to assess fit of the program with the needs of the population and the availability of the financial and personnel resources needed for implementation and evaluation. Initial site preparation generally takes from 6 months to 2 years. Following implementation of the program, they continue to work with key stakeholders in order to expand it with sustainable financing and organizational and community support.

*Trainers* with expertise and clinical experience in the model conduct training sessions for nurse home visitors and their supervisors, instructing them in the intervention itself and in applying the theoretical framework and home visit guidelines in their work with families who enrol in the program. Training is provided in three sessions, spaced over approximately 14 months, allowing nurses to acquire new skills and resources coincident with the needs of the families they are serving. The first session provides orientation to the model and prepares nurses to work with families during pregnancy; the second session prepares

nurses to work with families during the child's infancy; and the third session focuses on work with families during the toddler period. Trainers also are available to local staff for guidance and consultation regarding problems they might encounter in implementing the program, through telephone conference calls, e-mail, and a newly developed listserve.

*The evaluation team*, in collaboration with site development specialists and trainers, work with leaders at each site to monitor the quality of key aspects of the program through data gathered via the Clinical Information System, to identify strengths and weaknesses at each site, and to eventually improve the quality of each program. To facilitate improvements in the quality of implementation of each program, we are developing a national network of sites so that leaders at each site will have the opportunity to regularly talk with their peers, share ideas, and solve problems as they arise.

### **The Future**

Based on lessons learned about what it takes to successfully replicate and sustain the NFP, the Center will undertake initiatives involving the dissemination of other effective community-based programs for families and children. For further information about the Center, visit our Web site at <[www.nccfc.org](http://www.nccfc.org)>.

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## **Stress and the Effects of Hospital Restructuring in Nurses**

**Esther R. Greenglass and Ronald J. Burke**

Cette étude examine l'ampleur du stress et l'épuisement professionnel chez les infirmières durant la restructuration des hôpitaux. Les résultats sont liés au travail, tels la satisfaction à l'égard de l'emploi et l'épuisement professionnel, ainsi qu'au domaine psychosomatique, par exemple la dépression. L'étude compare les effets découlant des initiatives de restructuration des hôpitaux à ceux qui sont attribuables à des agents stressants spécifiques au travail, tels que la charge de travail, l'évincement (lorsqu'une infirmière en remplace une autre en raison de l'ancienneté) et le recours à du personnel non qualifié pour accomplir le travail des infirmières. Elle se penche aussi sur le rôle des ressources personnelles, dont l'autoefficacité et la collaboration. Les résultats ont révélé que, dans les hôpitaux en processus de restructuration, la charge de travail constitue la variable explicative d'épuisement la plus importante et la plus fréquente en ce qui a trait aux infirmières. Cela se manifeste par une diminution de la satisfaction au travail, de l'efficacité, et de la sécurité d'emploi. La charge de travail accrue contribue aussi à la dépression, au désillusionnement et à l'anxiété. L'évincement concourt à l'insécurité d'emploi, à la dépression et à l'anxiété. Ces résultats font mention des effets néfastes particuliers de la restructuration des hôpitaux et de leurs conséquences. L'importance qu'on accorde à l'implantation de pratiques appropriées pour régler les problèmes de charge de travail se traduit chez les infirmières par la satisfaction professionnelle, ou la dépression et l'anxiété. De telles pratiques doivent faire partie d'un processus continu d'interaction entre l'administration de l'hôpital et les infirmières.

This study examines the extent of stress and burnout experienced by nurses during hospital restructuring. It includes both job-related outcomes such as job satisfaction and burnout, and psychosomatic outcomes such as depression. The study compares effects attributable to number of hospital restructuring initiatives with those attributable to specific work stressors such as workload, bumping (where one nurse replaces another due to greater seniority), and use of unlicensed personnel to do the work of nurses. It also examines the role of personal resources including self-efficacy and coping. Results show that, in hospitals undergoing restructuring, workload is the most significant and consistent predictor of distress in nurses, as manifested in lower job satisfaction, professional efficacy, and job security. Greater workload also contributed to depression, cynicism, and anxiety. The practice of bumping contributed to job insecurity, depression, and anxiety. The results point to specific deleterious effects of hospital restructuring. Implications of the findings are discussed. The extent to which workload issues are managed through appropriate practices can be expected to match the extent of nurses' experience of either job satisfaction or depression and anxiety. Such practices need to be part of an ongoing process of interaction between the hospital administration and nurses.

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Restructuring and downsizing are occurring increasingly throughout the private and public spheres. In Canada, downsizing is being imposed on the health-care system and hospitals are being restructured, merged, or closed, resulting in the loss of thousands of jobs. In the province of Ontario, it has been estimated that, as a result of the planned closure of 10 hospitals in Toronto alone, 10,000 workers would lose their jobs ("Big triumphs over small," 1997; "Public health units struggle," 1997). Since most of the nurses affected by such measures are employed in hospitals, and since hospital closures are occurring everywhere, nurses are faced with increasing job shortages.

With fewer qualified staff to care for patients, the workload of nurses has increased (Ontario Nurses' Association, 1996). Nurses are reporting more stress and burnout, greater job insecurity, and a lowering of morale (Armstrong-Stassen, 1994; Bourbonnais, Comeau, Vezina, & Dion, 1998). Work overload predicts negative mental health outcomes in nurses (Tyler & Cushway, 1995), job dissatisfaction (Schaefer & Moos, 1993), and burnout (Armstrong-Stassen, Cameron, & Horsburgh, 1994) correlated with depression and anxiety (Belcastro & Gold, 1983; Greenglass, 1991; Schaufeli & Enzmann, 1998); these results have also been reported in teachers (Greenglass, Burke, & Ondrack, 1990).

Hospital restructuring is associated with stressful changes such as deterioration in facilities and services, bed closures, layoffs, bumping (where one nurse replaces another due to greater seniority), and use of unlicensed health-care personnel to replace trained nurses. This "deskilling" of health-care services as a cost-saving measure (Registered Nurses Association of Ontario, 1999) has resulted in lower levels of patient care. It has also resulted in increased nursing workloads, since nurses are often responsible for the training and supervision of unlicensed workers (Gzowski, 1997). Distress levels experienced during hospital restructuring vary with the personal coping resources used. People who believe that outcomes are within their control tend to engage in control coping, while people who believe that outcomes occur by chance tend to resort to escape coping (Lefcourt & Davidson-Katz, 1991). Those who use control coping experience reduced distress compared to those who use escape coping (Greenglass, 1988). Layoff survivors who use escape coping have reported lower job performance and higher intent to leave the organization (Armstrong-Stassen, 1994). Control coping is associated with greater commitment to the organization. Self-efficacy, another personal resource, reflects optimistic self-beliefs about ability to deal effectively with demands (Bandura, 1992). Low self-efficacy is central in the etiology of burnout (Cherniss, 1990); burnout is inconsistent with a sense of self-efficacy (Leiter, 1991). In hos-

pitals being downsized, nurses high in self-efficacy tend to experience less distress and have more professional commitment than those low in self-efficacy.

Research suggests that job variables play a role in the degree of job insecurity felt by employees during downsizing. For example, part-time nurses experience more job insecurity than full-time nurses (Armstrong, Cameron, & Horsburgh, 1996). Hospital size (in terms of number of beds) can also play a part in nurses' reaction to downsizing, and large hospitals in Ontario have borne the brunt of the province's \$435 million in hospital cuts ("MDs step up protest," 1996). Nurses employed in larger hospitals experience greater job insecurity because of the higher number of layoffs. Length of employment in a hospital is another factor influencing a nurse's reaction to downsizing (Bartz & Maloney, 1986). Amount of time in nursing is related to burnout level during hospital restructuring (Chiriboga & Bailey, 1986), and whether or not a nurse has supervisory responsibilities is associated with reaction to downsizing. With the increased hiring of unlicensed health-care workers, nurses are being called upon to supervise and train these personnel, in addition to their other duties (Gzowski, 1997).

Demographic variables may play a part in nurses' reactions to hospital downsizing. Most nurses are women, many with families, and child care falls disproportionately to women (Biernat & Wortman, 1991). Parenting may result in additional stressors for nurses who are experiencing job insecurity during downsizing. A nurse's age may be a factor in her reaction to downsizing. Younger nurses report more depersonalization, one of the three burnout components of the Maslach Burnout Inventory (Maslach & Jackson, 1986). Perhaps older nurses experience less depersonalization because they have stayed in nursing as a result of personal involvement with patients (Robinson et al., 1991). Chiriboga and Bailey (1986) report an inverse relationship between age and burnout. Older nurses have been found to have lower stress levels during hospital downsizing (Kuhrik, Kuhrik, Katz, & Moore, 1996). Stress increases with nurse education (Tyler & Ellison, 1994); highly trained nurses perceive more stress, particularly from "conflict with doctors" and "workload" (Tyler & Cushway, 1995), which would be exacerbated during downsizing. The size of the community in which nurses work may be a factor in their reaction. Downsizing and tight budgets are a problem in smaller communities, where cutbacks make it difficult for hospitals to offer training in specialty nursing (Boyer, 1996).

The effects of downsizing can be understood within a stress-and-coping framework. Downsizing presents situational dimensions that

can elicit job-related and psychosomatic outcomes. Job outcomes include job insecurity, job dissatisfaction, and burnout, while psychosomatic outcomes include anxiety and depression. Outcomes are seen as related to organizational demands and to personal resources (coping and self-efficacy). Hospitals vary in the extent to which they are undergoing restructuring that may be quantified by computing the number of restructuring initiatives. Hospital restructuring measures are expected to be positively related to more nurse distress, as reflected in outcome measures.

A comprehensive framework was developed to guide selection of measures and data analyses. Predictors of job-related and psychosomatic outcomes in nurses are compared in two conditions. In model 1 the independent variable is the number of restructuring initiatives on the restructuring initiatives index (RII) undertaken by the hospital, such as layoffs, job sharing, bed closures, and unit closures. In model 2 the outcomes are studied in relation to three specific work stressors: workload, bumping, and use of unlicensed personnel. In both models the analyses use four panels of predictors (demographic, job variables, work stressors, and personal resources) and two sets of outcomes (job-related and psychosomatic). In model 1 the stressor is the number of restructuring initiatives. In model 2 the stressors are workload, bumping, and use of unlicensed personnel. The object of the research was to compare the outcomes of number of restructuring initiatives (model 1) with those of specific stressors (model 2). Model 2 was expected to be a better predictor of outcomes, since it is not the *number* of restructuring initiatives that is important, but their *impact*. Figure 1 presents schematic representations of models 1 and 2.

## Method

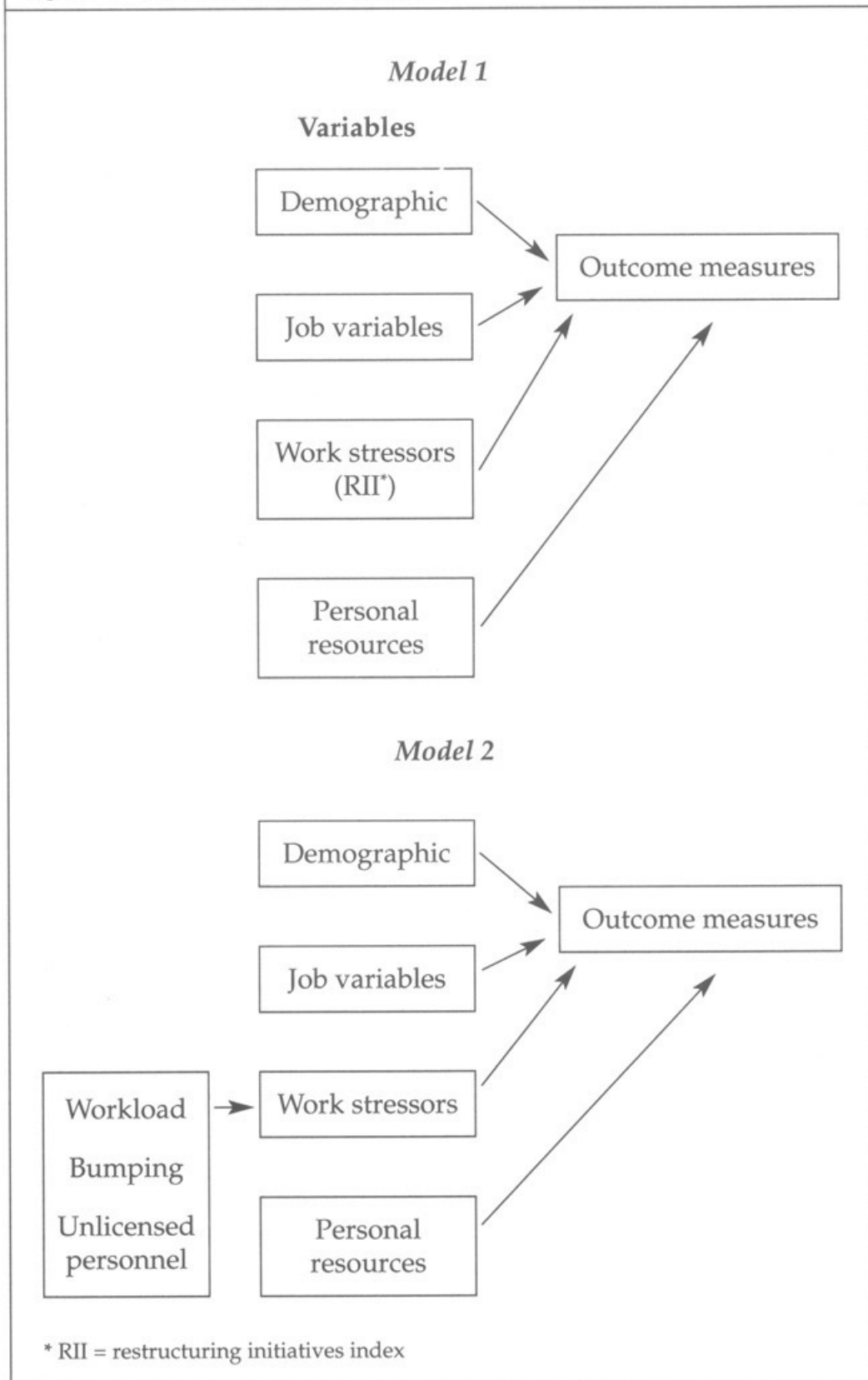
### *Procedure*

Data were collected using an anonymous questionnaire mailed out to 3,892 hospital nurses in the province of Ontario. The sample was chosen from among the nursing union's 45,000 members using a computer-generated randomized program. A total of 1,363 questionnaires were returned in the self-addressed, stamped envelope provided, yielding a response rate of 35%.

### *Measures*

**Outcome measures.** *Job-related outcomes* include burnout, impact of restructuring, job insecurity, and job satisfaction. The MBI-General

**Figure 1** *Models 1 and 2: Variables Predicting Outcome Measures*



Survey (Schaufeli, Leiter, Maslach, & Jackson, 1996) was used to measure three burnout components — emotional exhaustion, cynicism, and professional efficacy. Emotional exhaustion ( $\alpha = 0.90$ ) refers to the concept of job stress, while cynicism ( $\alpha = 0.82$ ) reflects an indifferent or distant attitude towards work. Professional efficacy ( $\alpha = 0.73$ ) refers to satisfaction with past and present accomplishments at work. The validity of the MBI-General Survey is reported in principal component analyses where emotional exhaustion was found to be associated with mental and physical strain, work overload, and role conflict. Professional efficacy has been found to be related to job satisfaction, organizational commitment, job involvement, and access to resources. Cynicism has been found to be related to the same constructs as emotional exhaustion but with negative secondary loadings on the attitudinal concepts associated with professional efficacy (Schaufeli et al., 1996).

The impact of restructuring scale (developed for this research) measures the extent to which nurses perceive that restructuring has compromised delivery of health-care services (seven items) ( $\alpha = 0.78$ ). Job insecurity ( $\alpha = 0.76$ ) (developed for this research) measures the degree to which nurses expect to experience negative job outcomes in 10 areas including layoff, termination, demotion, and deterioration in working conditions. Job satisfaction (Quinn & Shepard, 1974) ( $\alpha = 0.82$ ) consists of five items relating to respondents' affective reaction to their jobs without reference to job factors. It correlates negatively with job anxiety and somatization, and positively with instrumental coping (Greenglass, 1993).

*Psychosomatic outcomes* include depression (11 items) ( $\alpha = 0.88$ ) and anxiety (seven items) ( $\alpha = 0.80$ ), assessed using the Hopkins Symptom Checklist (HSCL) (Derogatis, Lipman, Rickels, Uhlenhuth, & Cori, 1979). Depression and anxiety have been found to correlate negatively with preventive coping in teachers (Greenglass & Burke, 1991).

**Work stressors.** The extent of restructuring was assessed using the 16-item restructuring initiatives index (RII) ( $\alpha = 0.69$ ), a composite measure designed for this study. Respondents indicated initiatives applicable to their hospital such as layoffs, job sharing, bed closures, and unit closures. RII scores were obtained by summing restructuring initiatives checked by the respondent. Workload ( $\alpha = 0.70$ ), consisting of four items including two from Armstrong-Stassen et al. (1996), measured the nurse's workload as a result of changes in the hospital. Bumping (two items) ( $\alpha = 0.60$ ) measured the extent to which staff changes occurred as a result of one nurse replacing another due to greater seniority. Use of unlicensed personnel (two items) ( $\alpha = 0.70$ )

assessed the extent to which unlicensed health-care personnel were used to replace trained nurses. The work stressors were developed for this research.

**Personal resources.** Latack's (1986) 28-item Coping Scale was used to measure control ( $\alpha = 0.86$ ) and escape coping ( $\alpha = 0.71$ ). Control coping consists of problem-focused actions and cognitions; escape coping consists of actions and cognitions indicative of avoidance. Control coping items correlate negatively with stress symptoms, while escapist coping items correlate positively. Leiter (1991) reports that control coping was found to correlate negatively with emotional exhaustion and depersonalization and positively with personal accomplishment on the MBI burnout subscales (Maslach & Jackson, 1986). Self-efficacy ( $\alpha = 0.87$ ) was assessed using a 10-item perceived self-efficacy scale (Schwarzer, 1993); this measure involves optimistic self-beliefs about dealing with critical demands that tax an individual's resources (Bandura, 1992). Leppin (1992) reports positive correlations between self-efficacy scores and self-esteem, and negative correlations between depression and self-efficacy and between anxiety and self-efficacy.

**Job variables.** Respondents also indicated whether they had supervisory duties, whether they worked full- or part-time, length of current employment, and number of beds in their hospital. Demographic variables include sex, age, education, whether a parent or not, and size of community.

### ***Respondents***

Respondents were primarily women (94.8%) employed in at least 11 different nursing units, with approximately two thirds in medical/surgical, intensive care/coronary, emergency, and obstetric units. One half worked part-time. Forty-five percent had supervisory duties. The communities in which they worked varied in population from 50,000 to over one million. About one half of the nurses worked in large hospitals of over 250 beds. On average, the nurses were employed 13 years in their current hospital. The majority were professional nurses who had completed an approved college or hospital nursing program. Eighty percent were married or living with a partner. Three quarters had children (approximately two). The average age of the respondents was 42.

**Table 1** *Correlation Matrix for Outcome Variables*

	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Control coping	-.07*	.34***	-.03	-.20***	.33***	.08**	.04	.14***	-.12***	-.10***	.08**	.09**	.08**	.01
2. Escape coping	...	.01	.09**	.29***	-.05	.02	.08**	-.12***	.13***	.09**	-.00	.01	.00	.05
3. Self-efficacy	...	...	-.13***	-.15***	.31***	.01	.00	.11***	-.25***	-.25***	-.01	-.00	.01	-.03
4. Emotional exhaustion	...	...	...	.58***	-.12***	.36***	.31***	-.53***	.43***	.40***	.18***	.46***	.17***	.11***
5. Cynicism	...	...	...	...	-.23***	.29***	.27***	-.58***	.39***	.32***	.11***	.29***	.10***	.11***
6. Professional efficacy	...	...	...	...	...	-.01	-.05	.26***	-.15***	-.12***	.01	-.07*	.04	-.03
7. Impact of restructuring	...	...	...	...	...	...	.32***	-.35***	.17***	.13***	.31***	.54***	.35***	.34***
8. Job insecurity <sup>1</sup>	...	...	...	...	...	...	...	-.26***	.27***	.23***	.19***	.28***	.19***	.16***
9. Job satisfaction	...	...	...	...	...	...	...	...	-.27***	-.25***	-.13***	-.40***	-.13***	.12***
10. Depression	...	...	...	...	...	...	...	...	...	.75***	.09**	.20***	.15***	.05
11. Anxiety	...	...	...	...	...	...	...	...	...	...	.09**	.16***	.13***	.01
12. Restructuring initiatives index (RII)	...	...	...	...	...	...	...	...	...	...	...	.20***	.25***	.22***
13. Amount of work	...	...	...	...	...	...	...	...	...	...	...	...	.25***	.18***
14. Bumping	...	...	...	...	...	...	...	...	...	...	...	...	...	.21***
15. Use of unlicensed personnel	...	...	...	...	...	...	...	...	...	...	...	...	...	...

\*  $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$

<sup>1</sup>The higher the score, the greater the job insecurity.

## **Results**

### ***Restructuring Initiatives***

Most respondents (94.9%) indicated that budget cuts had occurred, followed by layoffs (94.0%) and bed closures (91.3%). In 88.3% of hospitals, the practice of bumping occurred. In 83.6% of hospitals, early retirement incentives were offered to staff. Close to 80% of hospitals were not filling job vacancies. Three quarters of respondents reported unit closures. Close to 70% of respondents said that they experienced wage and hiring freezes. Approximately one half of respondents reported overtime restrictions on employment or having to switch to a part-time position. Respondents reported an average of 9.57 ( $SD = 2.64$ ,  $n = 1,362$ ) restructuring initiatives at their hospital.

Cronbach alphas on combined variables indicated that reliabilities of the variables were acceptably high (0.70 or higher).

Table 1 presents a correlation matrix of variables. Results show that the RII and the impact of restructuring correlated positively with control coping, workload, bumping, use of unlicensed personnel, emotional exhaustion, cynicism, depression, anxiety, and job insecurity. The higher the RII score and the greater the impact of restructuring, the lower the job satisfaction. Thus the RII and the impact of restructuring measure were related to job insecurity and stressors associated with downsizing as well as to psychosomatic outcomes. Job insecurity correlated positively with emotional exhaustion, cynicism, depression, anxiety, workload, bumping, and use of unlicensed personnel. Workload correlated positively with control coping, emotional exhaustion, cynicism, depression, and anxiety, and negatively with professional efficacy and job satisfaction. Use of unlicensed personnel correlated positively with emotional exhaustion, cynicism, workload, and bumping. Bumping correlated positively with emotional exhaustion, cynicism, depression, and anxiety. Thus the three stressors of workload, bumping, and use of unlicensed personnel were positively related to burnout and psychosomatic outcomes.

### ***Statistical Analyses***

In order to determine the contribution of variables to outcomes, hierarchical multiple regressions were conducted, with variables entered in blocks. This model parallels those used to study stress and coping (e.g., Cooper & Marshall, 1976; Edwards, 1992) by simultaneously examining several panels of variables. Two hierarchical regression models were

used to compare the effects of stressors and restructuring initiatives. The models were identical except for the variables entered in the third block. The *first* block (5) entered were demographic (control) variables including sex, age, education, whether a parent, and size of community. The *second* block (4) were job-related variables including hospital size, length of current employment, whether job included supervisory duties, and whether full- or part-time. The *third* block consisted of either the RII (model 1) or specific stressors (model 2). The *fourth* block (3) were resource variables such as control coping, escape coping, and self-efficacy. This plan considers the increment in variance explained in each dependent variable when other predictors were previously entered. Outcomes were job-related or psychosomatic. Job-related outcomes included impact of restructuring, emotional exhaustion, job satisfaction, cynicism, job insecurity, and professional efficacy. Psychosomatic outcomes were depression and anxiety.

### *Multiple Regression Results — Model 1*

Table 2 presents the multiple regression results where the RII was the stressor (model 1), total R Square, increase in variance in outcome variables accounted for by each block of variables, and significance levels. Results show that the four blocks accounted for between 7% and 16% of total variance, depending on the outcome measure. Increase in explained variance due to demographic variables, job variables, and the RII was small. Resources accounted for between 1% and 14% of the variance in outcome measures. The RII accounted for 8% or less of the variance in outcome measures (see Table 2).

### *Multiple Regression Results — Model 2*

Total variance accounted for in outcome variables was greater when specific work stressors were entered in the Stressor Block (model 2). Using model 2, the four blocks of variables accounted for between 13% and 39% of the total variance in outcome variables. Increase in variance due solely to the stressor block ranged from 1% to 39%; approximately twice as much of the variance in outcome measures was accounted for in model 2 than model 1. Outcomes showing the greatest increase in variance due to stressors were impact of restructuring, emotional exhaustion, and job satisfaction (see Table 3).

Of the three stressors examined, workload emerged as the most significant predictor of outcomes. Workload was a significant and positive contributor to impact of restructuring ( $\beta = .45, t = 16.29^{***}$ ),<sup>1</sup> emotional

<sup>1</sup>  $***p < .001$   $*p < .05$ .

**Table 2** *Hierarchical Multiple Regression Results: Model 1*

Outcome Variable	Increase in Variance When Restructuring Initiatives Index Is the Stressor				
	Blocks				
	Total R <sup>2</sup>	I Demographic	II Job	III <sup>1</sup> Work stressors	IV Personal resources
Impact of restructuring	0.13	0.03***	0.01	0.08***	0.01
Emotional exhaustion	0.10	0.02**	0.04***	0.02***	0.02***
Job satisfaction	0.07	0.02**	0.00	0.01***	0.04***
Cynicism	0.14	0.01*	0.00	0.01***	0.12***
Job insecurity <sup>2</sup>	0.11	0.02**	0.04***	0.03***	0.02**
Professional efficacy	0.16	0.01	0.01*	0.00	0.14***
Depression	0.11	0.00	0.01*	0.01***	0.09***
Anxiety	0.10	0.00	0.01	0.01***	0.08**

<sup>1</sup> The restructuring initiatives index is the stressor.  
<sup>2</sup> The higher the score, the greater the job insecurity.  
\*  $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$

**Table 3** *Hierarchical Multiple Regression Results: Model 2*

Outcome Variable	Increase in Variance with Three Work Stressors				
	Blocks				
	Total R <sup>2</sup>	I Demographic	II Job	III <sup>1</sup> Work stressors	IV Personal resources
Impact of restructuring	0.39	0.03***	0.01	0.35***	0.00
Emotional exhaustion	0.27	0.01*	0.03***	0.20***	0.03***
Job satisfaction	0.22	0.02**	0.00	0.15***	0.05***
Cynicism	0.24	0.01	0.01	0.09***	0.13***
Job insecurity <sup>2</sup>	0.19	0.03***	0.05***	0.09***	0.02***
Professional efficacy	0.18	0.01*	0.02**	0.01*	0.14***
Depression	0.16	0.00	0.01	0.06***	0.09***
Anxiety	0.13	0.00	0.01	0.04***	0.08***

<sup>1</sup> Workload, bumping, and unlicensed personnel are the stressors.  
<sup>2</sup> The higher the score, the greater the job insecurity.  
\*  $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$

exhaustion ( $\beta = .43, t = 14.36^{***}$ ), cynicism ( $\beta = .30, t = 9.02^{***}$ ), job insecurity ( $\beta = .23, t = 6.97^{***}$ ), depression ( $\beta = .18, t = 5.18^{***}$ ), and anxiety ( $\beta = .15, t = 4.26^{***}$ ), and a negative contributor to job satisfaction ( $\beta = -.39, t = -12.27^{***}$ ) and professional efficacy ( $\beta = -.09, t = -2.58^*$ ).

Bumping contributed positively to impact of restructuring ( $\beta = .18, t = 6.55^{***}$ ), job insecurity ( $\beta = .07, t = 2.20^*$ ), depression ( $\beta = .09, t = 2.66^{**}$ ), anxiety ( $\beta = .11, t = 3.08^{**}$ ), and professional efficacy ( $\beta = .08, t = 2.37^*$ ). Use of unlicensed personnel contributed to impact of restructuring ( $\beta = .36, t = 6.85^{***}$ ) and job insecurity ( $\beta = .21, t = 2.92^{**}$ ).

### **Discussion**

Increased workload was found to be the most significant and consistent predictor of stress among nurses in hospitals being downsized. The greater the nurse's workload as a result of changes in the hospital, the greater the impact of restructuring and the greater the nurse's emotional exhaustion, cynicism, depression, and anxiety. Increased workload was also found to be associated with decreased job satisfaction, professional efficacy, and job security. The hospital's practices of bumping and using unlicensed personnel contributed to stress in nurses, but to a lesser degree. These practices resulted in greater impact of restructuring and less job security. In comparison to specific work stressors, the RII was a less influential factor in the outcomes.

The present results extend those of previous research showing that work overload is a significant predictor of stress and burnout in nurses (Armstrong-Stassen et al., 1994; Moore, Kuhrik, Kuhrik, & Katz, 1996; Tyler & Cushway, 1995). When hospitals are downsizing — cutting budgets and reducing nursing personnel — surviving nurses are required to do more work in less time. Thus it is not surprising that the respondents in the present study showed greater cynicism, depression, anxiety, and emotional exhaustion. An additional finding is that, compared to work stressors, demographic factors contributed less to the variance in outcome measures. Variables such as presence or absence of supervisory duties, full-time versus part-time work, length of current employment, and hospital size were also less important than stressors in determining outcomes. As expected, individual resources, including coping and self-efficacy, contributed significantly to outcomes. Nurses, like other employees, need personal coping strategies for dealing with the chaos associated with restructuring. Nurses who show higher levels of self-efficacy cope correspondingly effectively with the changes in their hospitals.

The stressors and outcome measures developed for this research were found to be valid measures. For example, the RII and the impact of restructuring scale were positively related to job insecurity, work stressors, and psychosomatic outcomes. Job insecurity was positively related to burnout, work stressors, and psychosomatic outcomes, thus providing evidence for its validity. The stressors were positively associated with burnout and psychosomatics, demonstrating their validity.

A limitation of the present study was a relatively low response rate, probably due in part to the length of the questionnaire (13 pages). However, the sample was representative of the general population of nurses on a number of key variables. For example, approximately 80% of nurses in Canada are employed in hospitals (Canadian Nurses Association, 1990). The average age of the nurses in the study was 42, compared to 44 in Ontario overall (Nursing Task Force, 1999). While 47% and 51% of the sample were employed full- and part-time, respectively, 49% and 47% of all nurses in Ontario were full- and part-time in 1997 (College of Nurses of Ontario, 1997). Most of the sample were women, similar to Ontario nurses in general. In the sample, nurses came from hospitals and communities of various sizes, while Ontario hospitals and communities in general vary in size. Forty-five percent of respondents stated they had supervisory duties in addition to their regular responsibilities, due to the need for registered nurses to supervise unlicensed health-care workers who have replaced registered nurses as a cost-saving measure (Gzowski, 1997). Taken together, these data indicate that the sample of nurses is representative of Ontario nurses.

These findings have implications for interventions that might be initiated by hospitals during restructuring. The significant betas for workload and bumping indicate their extensive influence on outcomes. If the deleterious effects of stressors such as workload are made known to hospital administrators, this finding may serve as a first step in the design of programs to ameliorate distress in nurses. Hospitals could be proactive in reducing stressful outcomes in nurses by implementing policies to limit increased workloads and teach nurses how to use more control-oriented coping in response to stress. Administrative changes are needed that will facilitate communication between nurses and administrators, including negotiations regarding workload. If workload issues are managed appropriately during restructuring, nurses should experience greater job satisfaction and less depression and anxiety. This will allow nurses to continue their work while retaining their sense of professional efficacy.

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## Critical Theory: Critical Methodology to Disciplinary Foundations in Nursing

Judy E Mill, Marion N. Allen, and Raymond A. Morrow

De plus en plus, dans les ouvrages portant sur la profession infirmière, les théoriciennes examinent l'utilisation de la théorie critique dans les soins infirmiers (surtout telle que comprise par Habermas) et bon nombre l'ont reconnue comme une méthode de recherche pour guider le développement des connaissances dans ce domaine. Cependant, on a peu analysé les conséquences générales de la théorie critique pour les soins infirmiers en tant que discipline. Une partie du problème provient de l'omission de différencier les implications des travaux antérieurs de Habermas sur les intérêts de la connaissance, et de sa théorie ultérieure appelée action communicative. Dans cet article, la théorie critique de Habermas est explorée selon deux dimensions : en tant que compte rendu métathéorique d'une méthode de théorie critique comme tradition de recherche; et en tant que théorie de l'action communicative dont les postulats dialogiques et normatifs ont des conséquences profondes pour une assise postfondamentale des soins infirmiers comme discipline et pratique professionnelle. Les auteures allèguent que la théorie critique est nécessaire pour les soins infirmiers et pourrait suffire comme base philosophique paradigmatique de cette discipline.

Increasingly in the nursing literature, theorists have examined the use of critical theory in nursing (especially as understood by Habermas) and many have advocated it as a research approach to guide knowledge development in nursing. There has been limited analysis, however, of critical theory's broader foundational implications for the discipline of nursing. Part of the difficulty stems from a failure to differentiate between the implications of Habermas's earlier work on knowledge interests and his later theory of communicative action. In this paper, Habermas's critical theory is explored along two dimensions: as a metatheoretical account of a methodology of critical theory as a research tradition; and as a theory of communicative action whose dialogical and normative assumptions have profound implications for a postfoundationalist grounding of nursing as a discipline and professional practice. The authors argue that critical theory is necessary for nursing and may be sufficient as a paradigmatic philosophical base for the discipline.

The encounter with critical scholarship can initially feel like a rupturing. In its milder forms, it may feel more like a gradual unraveling that loosens more and more layers of assumption and belief.... At its best, critical scholarship in nursing provides both the loosening

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and reweaving dimensions of critical reflexivity. (Thompson, 1987, pp. 36-37)

A decade ago, Thompson (1987) reviewed the development of critical scholarship in nursing and highlighted its role in exposing and challenging relations of domination that exist within the lives of nurses and the larger context of nursing. Thompson suggested that critical scholarship, founded on and congruent with the tradition of critical theory, would enable nurses to challenge the status quo and begin to understand that "the established order is only one possible way of constructing reality" (p. 33). Since the publication of Thompson's review there has been further discussion in the nursing literature regarding the use of critical theory as a research approach to guide knowledge development.

As a result of this exploration, critical theory has gained some credibility within nursing. Nurse theorists have advocated the use of critical theory for a specific purpose (McLain, 1988) or setting (Reutter, 2000; Stevens & Hall, 1992), as a framework for nursing education (Harden, 1996; Reutter & Williamson, 2000; Thompson, 1987), as a paradigm to guide nursing research (Lutz, Jones, & Kendall, 1997; Maeve, 1999; Reutter, Neufeld, & Harrison, 1995), and as the overriding framework to guide development of the discipline (Holter, 1988; Lorensen, 1988). In the nursing research and methodology literature there has been a tendency to argue that critical theory provides a complementary methodology to traditional research traditions for the development of emancipatory knowledge. A position that must be considered, however, is that critical theory has the potential to provide the *broad philosophical foundation required by the discipline of nursing*. We will argue that various misunderstandings and a general failure to refer to the more recent work of Habermas have precluded adequate exploration of this possibility.

Two basic questions are at stake in considering the foundational potential of critical theory for nursing. On the one hand, it implies that critical theory provides metatheoretical foundations and suggestive points of departure for a theory of society necessary for a nursing research tradition. Fundamental to this position is the proposal that critical theory can provide the integrative framework for the development of empirical, hermeneutic, and emancipatory knowledge. This does not imply that critical theory displaces specialized modes of inquiry, though these remain incomplete. The general claim is, rather, that critical theory provides a framework for potentially understanding and analyzing the relationships among different forms of inquiry with spe-

cific methodologies and research problems. Critical theory's ability to contextualize the production and uses of knowledge should sensitize any research project to potential problems of reflexivity. On the other hand, as a research tradition critical theory is also uniquely sensitive to the normative implications of research and professional practice. It is thus foundational not merely as a framework for understanding research, but also as a basis for considering the normative implications of nursing in relation to public policy, health-care ethics, and the interpretation of human needs.

In this paper we will attempt to defend a stronger conception of the role of critical theory for nursing than currently envisioned. It will be contended that critical theory needs further exploration and elaboration as the basis of a more encompassing philosophical framework for nursing science. The essential premise is that nursing is grounded in a dialogical relationship with persons and bound by the distinctive features of the care and healing of the human body. The comprehensive features of that dialogical relationship can be revealed only in a theory of communicative intersubjectivity of the type developed in Habermas's more recent work. Though many traditions provide knowledge essential for understanding human illness, only critical theory provides the potential conceptual resources for mediating between and synthesizing these diverse contributions.

### **Varieties of Critical Theory**

In order to grasp the specific features of the form of critical theory to be discussed here, a brief historical introduction is necessary. The term originates with the so-called Frankfurt School in Germany in the 1930s, which drew out the radical implications of historical materialism for a theory of knowledge (Held, 1980). The most enduring aspect of this early critical theory can be found in its anticipation of environmental theory, especially the consequences of the endless, unregulated expansion of technology (Leiss, 1990). Today the term critical theory is applied to a number of approaches that share a radically historical theory of knowledge and a conflict theory of society in which the domination of the social subject is a central theme (Calhoun, 1995; Morrow, 1994). In this broader sense, otherwise diverse theorists such as Giddens, Bourdieu, and Foucault have been considered critical theorists. The focus here will be on the approach of Jürgen Habermas, because of his impact on discussions in the nursing literature and the pertinence of his work in recasting the foundations of the social sciences.

Habermas's work developed in two phases (McCarthy, 1978). The first phase, in the 1960s, was directed towards a critique of positivism, especially the ideological uses of science and technology (Habermas, 1970). The most well-known outcome here was the distinction among three interests in knowledge: empirical analysis, hermeneutic interpretation, and critiques of domination (Habermas, 1971). It is this approach that has been identified in nursing and other fields as a tradition of critical research. Knowledge based on the control of nature is referred to as technical knowledge and can be pursued using empirical-analytic techniques that are in part application to social relations. Historical-hermeneutic techniques will reveal practical knowledge — that is, based on understanding. Practical knowledge in this instance refers to knowledge that allows "for an inter-subjective and in-depth perception of the social world" (Kendall, 1992, p. 6), as opposed to its common use in nursing to mean "knowledge that gives direction for the activities of practitioners" (Orem, 1988, p. 77). The pursuit of emancipatory knowledge, through a critical dialectic, leads to self-reflective knowledge and freedom from oppression. Habermas stressed the complementary rather than competing nature of the different knowledge interests (Habermas, 1971; Morrow, 1994).

The second phase of Habermas's work is associated with the theory of communicative action (Habermas, 1984, 1987a, 1987b). Though not rejecting the general conclusions of his earlier theory, he engages in a self-critique that recognizes that his theory of knowledge interests was too "foundationalist" in making excessive claims about the status of critique as a form of "knowledge." To this extent, this shift reflects a response to emerging postmodern critiques of knowledge as a literal representation of reality (Rosenau, 1992). Habermas's general strategy is to expand and differentiate concept reason (and rationality), rather than abandon it in the name of difference or the relativity of all claims to knowledge. The task, he suggests, is to see "the unity of reason in the diversity of its voices" (1992, p. 115). Hence, Habermas's pragmatic position seeks to oppose strong postmodernist and poststructuralist epistemologies that concluded representation was impossible and all knowledge relative, as mere effects of "discourse" (1987a).

Habermas's position outlined in his theory of communicative action is "postmetaphysical" or anti-foundationalist in refusing to claim some primary epistemological bedrock (objective) representations that absolutely guarantee knowledge (Habermas, 1992). At the same time, he points to pragmatic justifications for the distinctive character of scientific knowledge and rational justifications of values. On the one hand, the production of scientific knowledge is procedurally grounded in par-

ticular types of communities committed to open, rational argumentation. On the other hand, the validity of knowledge is ontologically plausible given the universal, deep structure of language and human interaction (Habermas, 1979). On these weaker foundations he sought to recast the claims of a critical theory of society in terms that could respond to the emerging, often indiscriminate attacks on scientific rationality associated with postmodern epistemologies.

The remainder of this essay will draw out some of the implications of Habermas's critical theory for nursing. First, it will be necessary to outline in greater detail the metatheory of critical theory — that is, its claims with respect to ontology, epistemology, and methodology. Second, we will discuss the normative or value implications of critical theory, especially in relation to the later theory of communicative action and communicative ethics. Third, we will consider the more specific methodological implications of critical theory as a research practice in nursing, with respect to both the general question of knowledge development and existing research influenced by critical theory. Finally, it will be proposed that such an understanding based on both phases of Habermas's work could facilitate moving critical theory from the margins of research practice in nursing to the centre of its self-understanding as a discipline and profession.

### **Metatheory and Critical Theory**

Critical theory is a research tradition that takes as its point of departure a critical metatheoretical perspective about the production and uses of knowledge. The ontology of critical theory assumes a mediating position between the extremes of subjectivism and objectivism and acknowledges the reflexive and subjective aspects of science (Morrow, 1994). The outcome is a position that argues for a critical realism at the level of ontology, but a pluralistic pragmatism and fallibilism in epistemology and methodology. Ontologically, critical realism asserts that although reality exists independently of our thoughts about it, empirical claims about its nature are always situated, contingent, and potentially fallible; an absolute representation of objective reality cannot be achieved (Guba & Lincoln, 1994; Morrow, 1994).

Habermas associates the theory of communicative action with an ontological paradigm shift in the human sciences, one related to the so-called linguistic turn in philosophy and related developments in poststructuralist theories of language (1992). The poststructuralist response has gained the most attention because of its tendency to view all representation as an illusion, a verbal game in which truth is essen-

tially a relation of power. Habermas's postfoundationalist approach, in contrast, points to an alternative that is grounded in a pragmatic approach that seeks to re-secure knowledge on a more practical basis. His proposed postmetaphysical approach rejects the reigning subject-object paradigm in favour of a subject-subject or communicative paradigm (1987b). What he means by a subject-object epistemology are those diverse approaches which begin with the assumption of an individual knower who comes to understand a discrete scientific object of inquiry.

The paradigm shift discussed by Habermas places the subject-subject relation at the centre of ontology and as the presupposition of all possible knowledge. His insights draw indirectly on Wittgenstein's critique of language and more directly on the pragmatism of Charles Sanders Peirce (Habermas, 1992). The knower cannot exist abstractly in Kant's sense; knowers can know only through the dialogical relations that constitute the debates that constitute scientific communities. This principle applies even more evidently in relations involving the application of objective knowledge to human subjects. Habermas's primary achievement has been to make the theory of dialogue central to the foundations of the human sciences in his theory of communicative action.

An analysis of the epistemological presuppositions of critical theory also reveals a position mediating between the extremes of positivism and anti-positivism. Critical theory is based on a belief that the pragmatic rationality of a theory is linked to its potential effectiveness in solving problems, rather than its foundationalist ability to confirm or falsify theory (Morrow, 1994). This position does not preclude the possibility that some social situations may necessitate the confirmation or falsification of theory, using empiricist techniques. Researchers using a critical theory approach rely on criteria derived through negotiated agreement with the community to distinguish knowledge from fiction (Allen, 1986). This position presupposes the plurality in forms of knowledge, acknowledges the value of all three knowledge interests, and assumes that knowledge is not discovered but created.

Critical theory incorporates both nomothetic and ideographic explanation in its conception of methodology. Nomothetic explanation refers to a method of inquiry with the goal of identifying and explaining patterns found in a population, whereas ideographic explanation is inquiry directed towards understanding the uniqueness of an individual case (Morrow, 1994). In order to uncover and interpret the structures of social systems, Morrow argues for the adoption of "two distinct

yet interdependent research logics: intensive explication and comparative generalization" (p. 211) — that is, intensive explication is required to understand individual actors and their relation to the larger social system. The patterns that are uncovered during intensive explication are compared to other, similar, systems in order to develop generalizations.

Critical theorists challenge the traditional reliance or privileging of one methodology or method to generate knowledge. A wide range of methodologies and methods, based on the assumptions of critical theory, are therefore advocated. As Campbell and Bunting (1991) point out, methods "can be used from any world view: thus the methods do not drive the assumptions" (p. 3). More fundamental to this research tradition, however, is the critical stance that is expected of the researcher in relation to the participants in the research and the production, use, and dissemination of knowledge. Methodologies based on critical theory provide a critique of ideology, attempt to reveal hidden power imbalances to achieve emancipation, and endeavour to ensure that knowledge is available in the public domain.

In light of the theory of communicative action, participatory action research (PAR) becomes even more important as an exemplar of an idealized methodology linking theory, research, and practice. Fundamental to the tradition of PAR is a focus on the issue of power as it relates to the definition and use of knowledge (Reason, 1994). The relationship between the inquirer and the subject in PAR attempts to break down the "subject-object binomial" (Fals-Borda, 1991, p. 5) taken up by traditional science, to achieve a subject-subject position. This methodology argues that the constructions of reality "become manifest not only through the 'mind', but through the *reflexive action* of persons and communities" (Reason, p. 333). Knowledge generated through PAR is no longer exclusively owned and disseminated by academia, but rather is shared by the community or group. The concept of "action" in PAR takes on a broad perspective that can include heightened understanding of a phenomenon or a raised level of consciousness.

In addition to the traditional range of methods used in qualitative and quantitative research approaches, critical theory emphasizes the use of dialectical strategies to understand contradictions in existing situations (Hedin, 1986; Moccia, 1986; Ray, 1992). Through dialogue and relational reasoning, such strategies explore relationships within and between phenomena by juxtaposing ideas with their antitheses. A unifying feature and central focus of critical theory is *immanent critique*, which involves the critical examination of the values and ideologies of

social institutions and their extant reality in order to uncover discrepancies between the two (Antonio, 1983). Within the nursing literature, the method of critical reflection appears to be synonymous with the notion of immanent critique (Campbell & Bunting, 1991; Hedin; Ray). The use of dialectical processes and critical reflection will "facilitate investigation of the social and cultural conditions, including political conditions of nursing and health care by critically interpreting 'reasoned moments' and intersubjective communication in social and political contexts" (Ray, p. 100). Consciousness raising, resulting in self-understanding and an enlightened awareness of phenomena, is another method central to methodologies based on critical theory (Henderson, 1995). Most recently, efforts have been made to show how Paulo Freire's critical pedagogy of conscientization converges with Habermas's conception of a paradigm shift towards communicative action (Morrow & Torres, in press).

### **Normative Theory: Ideology Critique and Communicative Ethics**

In addition to the pursuit of technical, practical, and emancipatory knowledge through different forms of inquiry, the development of normative theory is an important goal of critical theorists. Normative theories are "concerned with what ought to be and, as a consequence, are associated broadly with the philosophical or metatheoretical field of ethics" (Morrow, 1994, p. 50). In the traditional scientific paradigm, normative theory is for the most part implicit and considered "not knowledge at all, [but] merely a type of nonrational belief" (Morrow, 1994, p. 50). Critical theory, on the other hand, takes the position that "social theory and normative theory are inevitably intertwined" (Morrow, 1994, p. 239) and attempts to make its normative claims explicit. Whereas critical theory began as a critique of value-freedom or taken-for-granted dominant values, in its more recent phase it has also responded to the value-relativism of postmodernism in the name of a procedural value universalism that is sensitive to cultural difference.

Several basic contexts of normative questioning can be identified: classical ideology critique; normative reflexivity in research; and communicative ethics as a foundation for theoretical and concrete ethical theory. Classical ideology critique is most familiar as forms of research that reveal how vested economic and social interests may distort organizational structures and public policies. Normative reflexivity in research is central to PAR based on an intersubjective and transactional stance, acknowledging that knowledge generated through inquiry is mediated by the values of the researcher in relation to those of clients

(Guba & Lincoln, 1994). The problematic of communicative ethics, central to Habermas's later theory of communicative action, is less familiar and requires a more extended introduction. The theory was developed in response to the ambiguity of critique as a process where the "enlightened" reveal the "false consciousness" of everyone else through possession of "critical science." Habermas argues that "in a process of enlightenment there can only be participants" (1973, p. 40). In his later work, Habermas addresses the challenge to traditional scientific and value "universalism" posed by postmodernist critiques of knowledge.

In response to challenges to universalism on the part of those who question the imposition of Eurocentric values by experts on marginal or non-Western populations, Habermas sought to expand the concept of normative reasoning by emphasizing the distinction between a procedural ethics and a content ethics. The basis for this distinction derives in part from the developmental cognitive psychology of Piaget and the moral development theory of Lawrence Kohlberg (Habermas, 1990). The genetic structuralism of Piaget is based on a distinction between the structure and content of developmental stages. For example, the formal operations necessary for mathematical calculations may equally be concerned with the hunting of game in a tribe or putting a man on the moon. Applied to moral development, this distinction suggests that the formal properties of moral reasoning can be analyzed independently of particular, concrete value codes (e.g., Christian, Muslim, Humanist).

This focus of critical theory's universality is thus on elucidating the universal features of the logic of moral reasoning at different stages of moral development. Such ethics are "communicative" because of the stress placed on the interactive aspects of moral thinking as part of networks of social relations (Benhabib & Dallmayr, 1990). Whereas each moral decision is concrete and situational (part of an individual or group biography), it cannot be judged by any external ethical system. All that a critical communicative ethics can do is initiate a dialogue by raising questions about the level of sophistication of moral reasoning and the potential consequences for actors.

These issues have played a particularly important role in recent feminist theory where debate has centred on the historical fact of differences in male and female moral reasoning, given that historically men use more formal ("universalistic") procedures whereas women make more situational choices based on concern for the "other" (Gilligan, 1982). Though we cannot examine these issues in detail here, the central point for our purposes is the way in which it has become

apparent that both "universal" and "concrete" dimensions are central to any "ethics" of care, a theme that could obviously be extended to nursing (Larrabee, 1993; Meehan, 1995).

### **Knowledge Development in Nursing**

Given the presuppositions of critical theory, the question for consideration is whether critical theory is sufficient as a paradigmatic framework for guiding the development of knowledge needed in nursing. The scholarly literature is permeated with debate regarding the type of knowledge required for the advancement of a discipline. In nursing, the debate is often centred on nursing's status as a scientific discipline, with the type of knowledge required dependent on where nursing is situated in the "sciences." Although this is important, our concern relates to how critical theory can provide the most comprehensive framework for unifying the themes alluded to in this debate. The authors take the position that nursing is a scientific discipline where that encompasses the biological, human, and practical sciences. We find it significant that a number of discussions attuned to the range of issues broadly converge with the position of critical theory, whether this is made explicit or not. Schultz and Meleis (1988) suggest the knowledge needed for the discipline ranges from "the seemingly intuitive 'knowing' of the experienced and expert nurses to the systematically verified knowledge of empirical researchers" (p. 217). To ensure that knowledge is useful for nursing practice, explanation must enable understanding of the specific case, as well as the development of theory. In relation to the type of knowledge required by nursing, Gortner (1993) argues that "in essence the case is being made for nomothetic and ideographic understandings and explanations" (p. 486).

Schultz and Meleis (1988) also point out that research is not the only medium for knowledge development. They caution against the sole reliance on empirical knowledge and suggest that clinical knowledge, needed to solve practice issues, is individual and personal and can be gained through expert clinical practice. As well, conceptual knowledge that is abstract and generalizable can be achieved through reflection upon the patterns that emerge from nursing phenomena and can be described in models and theories. A range of methodologies is required to capture these different types of knowledge.

A conceptualization of the patterns of knowing useful to the nursing discipline is offered by Carper (1978). Like Schultz and Meleis, Carper argues that nursing requires empirics (the science of nursing) and aesthetics (the art of nursing), which are comparable to technical

and practical knowledge. In addition, Carper advocates for the inclusion of personal knowledge and ethical knowledge (moral knowledge) for the discipline. The author suggests that each type of knowledge is necessary but not sufficient to answer the questions relevant to the discipline of nursing. Holter (1988) draws a comparison between the four patterns of knowing advocated by Carper and the three knowledge interests proposed by Habermas, and concludes that Habermas's three knowledge interests are evident within Carper's patterns of knowing.

Moccia (1986) articulates the need for knowledge about the relationship between people and their social, political, and economic systems, because nursing is concerned with people as biopsychosocial beings. Similarly, Stevens (1989) argues that nursing must broaden its traditional views of environment to include social, political, and economic factors as they influence health. For example, social factors such as poverty, unemployment, poor housing, and inadequate nutrition have been identified as key determinants of health (Stevens & Hall, 1992). Knowledge that examines the influence of oppression on health (Kendall, 1992) and nursing (Bent, 1993) has also been advocated. Stevens challenges nursing to "uncover the disparate gender priorities in health, health care delivery, and health care regulatory mechanisms" (p. 63). Harden (1996) extends the notion of oppression in nursing to a more personal level and stresses that in order to give humanistic care, nurses must become aware of their oppression as both women and nurses. Kendall charges nurses with perpetuating oppression in their work by participating in systems that focus on adaptation and coping. The need for emancipatory knowledge for the discipline of nursing has been stressed by several nurse theorists as well (Allen, 1985; Kim & Holter, 1995; Schultz & Meleis, 1988). These theorists recognize that empirical-analytic and historical-hermeneutic knowledge interests are able to answer only questions relating to *what is* and therefore critical-emancipatory knowledge must be sought to answer questions of *what ought to be* (Marshall, 1994).

### **Critical Theory and Nursing**

Although there is some discussion in the literature relating to the necessity and adequacy of critical theory as a philosophical foundation for nursing, more emphasis appears to have been given to establishing its legitimacy as a research tradition. Several authors (Allen, 1985; Campbell & Bunting, 1991; Hedin, 1986; Kendall, 1992; Thompson, 1987) support the position that critical theory is essential for the development of knowledge in nursing. Critical theory is capable of develop-

ing knowledge that exposes inequities in health (Reutter, 2000), that is emancipatory for individuals, groups, and communities (Campbell & Bunting; Hedin), and that leads to understanding of the broad social, economic, and political factors that influence health (Reutter & Williamson, 2000). Allen (1985) cautions against the sole use of empirical-analytic and interpretive models of science, because "neither can distinguish between patterns or regularities...that are universal, or inherently human, and those that are a function of ideology or misrecognition" (p. 61). Critical science is necessary, he argues, because it takes as a central concern the issue of misrecognition and makes it explicit.

The adequacy of critical theory as a framework for the discipline has received some debate in the literature. Several nurse theorists (Allen, 1985, 1986; Cull-Wilby & Pepin, 1987) have suggested that critical theory should supplement, but not supplant, the use of empiricism and hermeneutics in nursing. They suggest that all three approaches can provide descriptive and explanatory knowledge and generate valuable nursing research. Gortner (1993) comments that critical theory cannot serve nursing exclusively because of its emphasis on social relations and liberating action. These authors appear to base their argument on the premise that the primary goal of critical theory is the pursuit of emancipatory knowledge and that as a research tradition critical theory is inadequate for the pursuit of empirical and hermeneutic knowledge.

A few nurse theorists (Holter, 1988; Lorensen, 1988) have explicitly argued that critical theory provides a comprehensive and sufficient philosophical foundation for nursing. Holter points out that critical theory's three processes of inquiry, and the range of knowledge ensuing from them, allow understanding of the biological, psychological, and sociological aspects of human nature that are required by nursing. Ray (1992) suggests that although critical theory may be limited in some nursing situations, its basic premises and assumptions are congruent with nursing philosophies and theories and therefore will enhance the discipline. The assumptions within critical theory that theory is inextricably linked to practice and that human activity always arises within a social context are similar to the assumptions of many nursing conceptualizations. Stevens (1989) argues that critical theory will enable nurses to identify "environmental conditions that constrain health and those that potentiate health" (p. 66). It is not clear from her argument, however, if she believes this to be an adequate framework for all knowledge development in nursing.

Wells (1995) demonstrates the use of critical theory for the development of knowledge about the relationship between individuals and their social, political, and economic environment, including the exposure of conditions that can constrain human activity. Although the primary focus of her research was the process of discharge decision-making, the use of a critical theory approach enabled her to go beyond this process "to include a focus on the play of forces underlying the process and the consequences of the process for those involved" (p. 48). This research demonstrated that the decision-making process was mediated to a greater extent by systemic forces than by the patients' clinical trajectory, and illustrates Habermas's argument that "social structure...is inseparable from social action...and that structure can constrain action" (Wells, p. 48).

The emphasis on action and change that is seen in critical theory has the potential to strengthen the connection between theory and practice in nursing. Hedin (1986) suggests that critical theory "is a means of consciousness raising in which theory and praxis become one, through its problem-posing nature" (p. 145). The participation of the "researched" in the research process will help to ensure that research programs inform practice and practice research. Current misalignments between theory and practice can be highlighted using critical theory (Holter, 1988), and mutual understanding between nurses and their clients can be promoted (Holter & Kim, 1995). Stevens and Hall (1992) believe that "the interwoven process of critical reflection and action is a theoretical key to effective community health nursing practice" (p. 3). By uncovering the links between social structures and health, critical theory has the potential to enhance the efficacy of our nursing interventions by ensuring that they are based on knowledge of the determinants of health.

### **From the Margins...to the Centre?**

Several authors (Cull-Wilby & Pepin, 1987; Seng, 1998; Thompson, 1987) have noted that critical theory and methodologies such as PAR have assumed a marginalized position in relation to more traditional research traditions. Thompson comments that the space occupied by critical scholars in nursing "is a marginal place" (p. 27). Similarly, Morrow (1994) suggests that participatory action research is sometimes "tolerated within or on the margins of existing institutions as part of experimental programs" (p. 319). An analysis of the use of PAR in nursing provides evidence that this phenomenon may be operative in our discipline.

Critical theory's position on the periphery of research traditions may be related not only to its potential to challenge the status quo (Kincheloe & McLaren, 1994; Seng, 1998), but also to its frequent misunderstanding in the literature (Cull-Wilby & Pepin, 1987; Held, 1980; Morrow, 1985, 1991, 1994; Scott, 1978). The misinterpretation has been attributed to its abstract vocabulary (Cull-Wilby & Pepin), the erroneous claim that critical theory is opposed to empirical inquiry (Morrow, 1991), and the failure by critical theorists to address its methodological implications (Holter & Kim, 1995; Morrow, 1985, 1994; Scott). In addition, critical theory's frequent description and discussion in the literature on qualitative research has contributed to the confusion by aligning critical theory with only qualitative methodologies. Critical theory does not usurp the territory of other specialized inquiries; its task is rather to introduce greater reflexivity into work and provide a theoretical vocabulary for understanding the relations among research domains and public policy.

The more serious objections and misunderstandings lie elsewhere: the very concept of critique that underlies its paradigmatic claims. Three typical objections need to be addressed here: that critical theory is pertinent only where overt oppression takes place; that critique is essentially negative and debunking in nature; and that the value perspective of critical theory is dogmatic and Eurocentric, hence inappropriate in an increasingly multicultural, globalized world.

The conceptualizations of *oppression* and *critique* that have come to be closely aligned with critical theory contribute to its misinterpretation in the literature. Frequently, oppression is defined narrowly to refer to a group that has been marginalized by a dominant group. Therefore, some nurse researchers erroneously conclude that if a research problem is not related to an "oppressed group" it cannot be studied within the rubric of critical theory. Yet a closer look at Habermas reveals that *domination* results from distorted communication of any kind. For example, it would be misleading to describe the historical relationship between physicians and nurses as one of "oppression," yet it can be viewed as a hierarchical relationship of professional domination with problematic consequences. Nursing research, in part inspired by critical theory, has sought to demonstrate these effects.

Similarly, the use of *critical* or *critique* in critical theory has, for some, become associated with a negative meaning as ideology critique (Morrow, 1994). Yet even this normative critique has a constructive, proactive side in its concern with provoking social subjects into critical reflection about their values and their relation with existing realities.

In this respect the success of critical theory is implicit above all in social movements where individuals mobilize to transform aspects of society in light of their new-found self-understanding (Habermas, 1981).

Finally, the aspiration to be critical has been charged with dogmatism, most notably an imposition of pseudo-universalistic values on marginal groups, a theme most evident in research on native and non-Western health care. Yet this question points to the fact that the most fundamental misunderstanding of critical theory in the nursing literature stems from a lack of awareness of the transactional principles of PAR and the philosophical implications of the later theory of communicative action. From this perspective, critique remains central but is complemented by a communicative ethics that has profound implications for nursing practice. The central insight of Habermas's later work is that critique, as the unveiling of domination, presupposes the reconstruction of the foundations of the human sciences that goes beyond the essentialism of traditional humanism. Central to this post-foundationalist humanism is the suggestion that humans and their possibilities, whether sick or well, can be revealed only through dialogical practices involving subject-subject relations. This humanness cannot be revealed directly by essentializing philosophical reflection any more than it can be adequately understood by viewing humans exclusively from an object-subject perspective. Instead, Habermas's theory of communicative action, supplemented by the insights of Freire and others into dialogue, provides a point of entry for a critical theory of nursing that involves both a strategy of research practice and a conception of nursing as a distinctive social practice grounded in scientifically informed relations of care.

While perhaps risking a position "at the margins," the authors argue that critical theory is necessary for nursing and conclude from this analysis that beyond its status as an empirical research tradition it may be sufficient as a paradigmatic philosophical base for the discipline and thus should stand at its "centre." Predicated on the assumption that knowledge development should not be constrained by a singular view nor methodology, critical theory challenges our traditional views and conceptualizations of knowledge and provokes us to re-examine how we come to know. "For nursing, critical theory thus offers a research perspective that may help to uncover the nature of enabling and/or restrictive practices, and thereby create a space for potential change and, ultimately, a better quality of care for patients" (Wells, 1995, p. 52). At the same time, its normative critique culminates in a communicative ethics of care in a manner that attempts to link the uni-

versal and the local in ways that should be central to the ethical foundations of nursing practice.

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## Book Review

### *Care Work: Gender, Labor and the Welfare State*

Edited by Madonna Harrington Meyer  
New York and London: Routledge, 2000, 348 pp.  
ISBN 0-41592-541-X cloth; 0-41592-542-8 pbk.

Reviewed by Joan C. Tronto

Although many of the essays in *Care Work* are focused exclusively on the United States, several are explicitly comparative and the issues discussed will be familiar to those concerned with care throughout industrialized societies. The essays are excellent and provide a valuable resource for anyone concerned with the current logic and organization of care.

Home care is not the primary focus of this volume. However, issues of care are increasingly being debated in the context of provision of services outside of institutional settings. This change of setting challenges all notions of the relationship of care to professional work and to traditional, gendered, family life. Many of the essays in *Care Work* are centred on these two incomparable spheres. Deborah Stone's contribution, "Curing by the Book," focuses on the conflict between getting the caring tasks done and the more central but amorphous aspects of care. She writes, "The essential elements of care can be squeezed out by the norms and rules of work in the public world. Talk gets displaced by tasks and is no longer a fully legitimate part of care. Love is taboo; detachment is correct. The idea of a client being special is wrong in the moral culture that defines fairness as treating everyone the same. Patience, the sense of devoting as much time as a person needs, is impossible when care becomes systematized and caregivers work on schedule" (p. 110). Stone's argument seems to be that such dilemmas are irresolvable. Francesca Cancian is slightly more optimistic in her contribution, "Paid Emotional Work." Cancian's research suggests that the institutional settings in which care is organized can determine whether the emotional elements of care are included, and how thoroughly they are treated.

A major theme of this book is how care is transformed when the boundary between public and private care is eroded. As Clare Ungerson succinctly puts it, "The dualism of paid and unpaid work is

dissolving...welfare states are searching for ways to underwrite the provision of care within households and kin networks through cash subvention given both to caregivers and to care recipients. The consequence is the marketization of intimacy and the commodification of care" (p. 69).

This commodification of care — the subsidization of family workers to provide care — is part of a general pattern as welfare states implement measures designed to contain costs. Attempts to curb rising state budgets for the provision of care result in care being increasingly forced out of the public domain. Once pushed back into the home, however, it is subject to the same cost-control pressures, as described by Trude Knijn in her account, "Marketing and the Struggling Logics of (Home) Care in the Netherlands." Alternatively, the state may simply divest itself of any responsibility for the delivery of care, so that it must be provided in the home by default. Since nursing homes are reluctant to take Medicaid patients, explain Madonna Harrington Meyer and Michelle Kesterke Storbakken in "Shifting the Burden Back to Families?", the result is a two-class system in which the poor are relegated to home care.

In raising such questions, this collection explores issues of race, class, and ethnicity. Mary Tuominen, in her account of child care, explores questions of class, race, and gender. African-American grandparents who take care of cocaine-exposed children are the subject of an essay by Assata Zerai. Many of the contributions also make it clear that when public care becomes heavily reliant on home care, less well-off individuals will receive poorer care. Robert Frost's familiar verse can increasingly be seen as describing the public provision of care: "Home is the place where, when you have to go there/They have to take you in." As long as neoliberals can revert to an image of care as a private concern, the more thoroughly class will determine who gives and receives adequate care.

"Home" is becoming the site of professional and semi-formal work and care. This collection of essays contains some of the best current thinking on the ways in which the boundaries between public and private care are being blurred.

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***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.

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**September 2002 (vol. 34, no. 2)**

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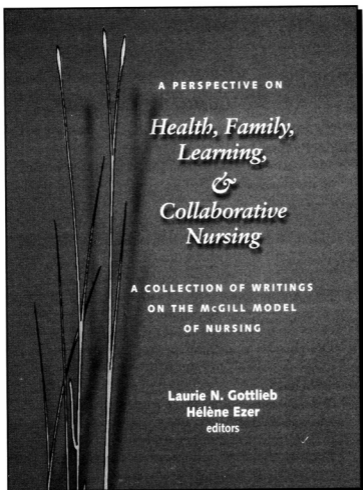
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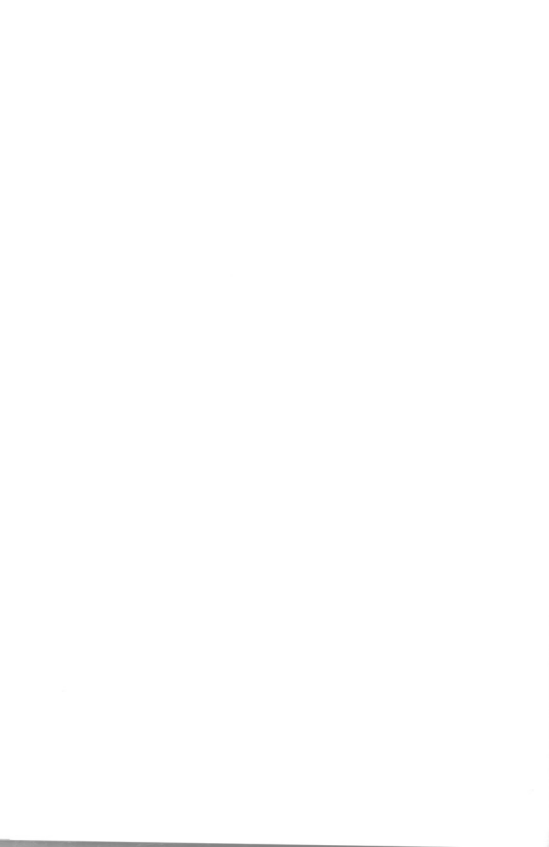
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