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SUMMER EDITORIAL

## **Developing Nursing's Future Knowledge Makers: Guarding Against Insularity**

Nineteen ninety-three will be recorded as a vintage year for Canadian nursing. The number of doctoral programs in nursing in Canadian universities continues to grow. Although McGill University admitted its first student into a nursing Ph.D. program in 1985 and has already graduated three students, the program was considered "ad hoc" in that it had not received government approval. This summer, the government of Quebec approved a joint Ph.D. program in Nursing between McGill University and the Université de Montréal. The University of Toronto also received approval this year. These universities join the University of Alberta and the University of British Columbia as official government-approved programs.

Success in establishing Ph.D. programs in nursing is the result of much hard work, years of planning, and cooperation among Canadian university schools of nursing and Canadian nursing leaders. During the past two decades, the Canadian nursing establishment worked tirelessly to persuade universities and governments to support doctoral programs in nursing. Although their early efforts met with disappointment and frustration, this period proved useful. It provided the time to consider fundamental issues related to knowledge development and to the training of the discipline's future "knowledge-makers".

In the meantime, some nurses who wanted doctoral preparation, enrolled in programs in related disciplines such as psychology, anthropology, sociology, education, epidemiology. They brought back to nursing the philosophical and scientific paradigms of their "adopted" disciplines. Inevitably, these methodologies shaped the kinds of questions nurses asked and the nature of the knowledge generated. This practice caused concern within the discipline. It was argued, and correctly so, that these methodologies were developed for disciplines that had different rules, practices, and needs from nursing. The act of "transplanting" methodologies developed specifically for one discipline to nursing often failed to meet the knowledge needs of nursing because of a poor fit between the methodology and the nature of nursing. Hence it was reasoned that if nursing was to develop its own knowledge base, paradigms and methodologies unique to the discipline could best be developed by scientists who understood and were sensitive to the discipline's conceptual schema, rules, realities, and practices. Therefore, preparing nurse-scientists in a discipline other than nursing was less than ideal. However, certain transient

benefits were spawned from this experience; benefits that need to be considered at this time.

I recently attended a lecture in the philosophy department at the University of Washington. The topic dealt with the development of knowledge and approaches to "knowledge-making". The lecturer outlined the problems inherent in philosophy's paradigms of knowledge making and proposed that Glaser and Strauss's "grounded theory" held promise as a method for generating knowledge in philosophy.

I was struck with how ignorant disciplines generally have tended to be of one another's philosophical underpinnings, scientific paradigms, and language. I thought how enriched nursing has been from the exposure to other disciplines and their methodologies. Indeed, this contact has facilitated discourse and communication between ourselves and other disciplines, has enabled us to understand their research, and has set the stage for interdisciplinary collaboration. It also has stimulated epistemological debate about models of scientific inquiry within nursing, debate that has resulted in the creation of new "knowledge-making" models. A case in point has been whether to adopt the logical-positivist paradigm or the empirical paradigm as nursing's scientific model. At the beginning of the debate, the proponents on each side focused on the differences, the incompatibilities. (Many still do.) More recently, new models of scientific inquiry are beginning to emerge that incorporate features of both. Thus, old models are being transformed rather than just being transplanted.

We are on the threshold of a new era in Canadian nursing. As we begin to develop our own community of scholars, we have to guard against the tendency of becoming too insular. The challenge that confronts us is how to continue to be open to all approaches of knowledge making without losing our distinct identity.

**Laurie Gottlieb**  
Editor

## **Le développement des futurs connaisseurs en sciences infirmières: La largesse d'esprit**

Mille neuf cent quatre-vingt-treize demeurera une bonne année dans les annales des sciences infirmières au Canada. Le nombre de programmes de doctorat en sciences infirmières dans les universités canadiennes ne cesse de croître. McGill University a accepté son premier étudiant au programme de doctorat en sciences infirmières en 1985 et trois étudiants ont déjà obtenu leur diplôme. Néanmoins, le programme fut considéré de façon *ad hoc* dans la mesure où il n'avait pas reçu l'aval du gouvernement. Cet été, le gouvernement du Québec a approuvé un programme de doctorat en sciences infirmières commun à McGill University et à l'Université de Montréal. Cette année également, la University of Toronto a été agréée. Ainsi, ces universités ainsi que la University of Alberta et la University of British Columbia offrent des programmes officiellement autorisés par le gouvernement.

La mise en place des programmes de doctorat en sciences infirmières est le résultat d'un travail assidu, d'années de planification, et de la collaboration entre les écoles en sciences infirmières des universités canadiennes et les dirigeants canadiens en sciences infirmières. Depuis maintenant vingt ans, les milieux dirigeants canadiens en sciences infirmières n'ont pas ménagé leurs efforts pour persuader les universités et les gouvernements de soutenir les programmes de doctorat en sciences infirmières. Au début, ils furent déçus et frustrés. Cependant, cette époque s'est révélée utile puisqu'elle a permis d'examiner les questions fondamentales liées au développement des connaissances et à la formation des futurs «connaisseurs» de la discipline.

Entre-temps, certaines infirmières désirant préparer un doctorat, s'inscrivirent dans des disciplines connexes, en psychologie, en anthropologie, en sociologie, en éducation ou en épidémiologie. Elles ramenèrent aux sciences infirmières les paradigmes philosophiques et scientifiques de leurs disciplines «d'adoption». Inévitablement, ces différentes méthodologies façonnèrent le genre de questions que les infirmières posaient et la nature de la connaissance ainsi produite. Cette pratique inquiéta. On disait, et c'est un fait, que ces méthodologies étaient élaborées pour des disciplines ayant d'autres règles, d'autres pratiques et d'autres besoins que ceux des sciences infirmières. Le fait de «transplanter» en sciences infirmières des méthodologies élaborées spécialement pour une certaine discipline bien souvent ne put satisfaire aux besoins de connaissances en sciences infirmières, car l'adéquation entre la méthodologie et la nature des sciences infirmières n'était pas correcte. Il

tomba donc sous le sens que si les sciences infirmières devaient élaborer leur propre base de connaissances, les paradigmes et les méthodologies propres à la discipline devaient être élaborés par des chercheurs qui comprenaient le schéma conceptuel de la discipline, ses règles, ses réalités et ses pratiques, et qui y étaient sensibles. Ainsi, préparer des chercheurs-infirmières dans une discipline autre que les sciences infirmières était nullement idéal. Pourtant, certains avantages passagers naquirent de cette expérience et ceux-ci doivent être maintenant pris en considération.

J'ai assisté récemment à une conférence à la faculté de philosophie de la University of Washington. On y traitait du développement de la connaissance et des diverses approches à l'élaboration des connaissances. L'orateur souligna les problèmes inhérents aux paradigmes philosophiques de l'élaboration des connaissances et suggéra que la *Grounded theory* (théorie fondamentale) de MM. Glaser et Strauss était prometteuse comme méthode d'élaboration des connaissances en philosophie.

J'étais frappée de constater combien les disciplines ignoraient généralement les autres accomplissements philosophiques, les paradigmes scientifiques et le langage. Je me disais que les sciences infirmières avaient été enrichies par cette exposition à d'autres disciplines et à leurs méthodologies. En effet, ce contact a facilité le discours et la communication entre nous et les autres disciplines, il nous a permis de comprendre leur recherche et de mettre en place une collaboration interdisciplinaire. Cela a également stimulé le débat épistémologique sur les modèles d'enquête scientifique au sein des sciences infirmières, débat qui a eu pour résultat la création de nouveaux modèles d'élaboration des connaissances. On s'est interrogé à savoir si l'on adoptait le paradigme logico-positiviste ou le paradigme empirique comme modèle scientifique pour les sciences infirmières. Au début du débat, les partisans de chaque paradigme se sont attachés aux différences et aux incompatibilités; bien d'autres s'y attachent encore. Plus récemment, de nouveaux modèles d'enquête scientifique ont commencé à émerger et ceux-ci comprennent des caractéristiques des deux paradigmes. Ainsi, les anciens modèles sont transformés et non pas seulement transplantés.

Nous sommes au seuil d'une ère nouvelle dans les sciences infirmières au Canada. Tandis que nous commençons à former notre propre communauté de spécialistes, nous devons garder notre largesse d'esprit. Le défi que nous devons relever, c'est de rester ouverts à toutes les approches d'élaboration des connaissances sans pour autant perdre notre identité.

**Laurie Gottlieb**  
Rédactrice en chef



# On Chronic Illness: Immigrant Women in Canada's Work Force – A Feminist Perspective

Joan M. Anderson, Connie Blue,  
Angela Holbrook, and Mirian Ng

Les données d'une étude comparative ethnographique ont été examinées afin de déterminer quels facteurs influencent la gestion de la maladie chez les immigrantes qui ne parlent pas Anglais dans la main-d'oeuvre au Canada. Par rapport aux Canadiennes d'origine européenne, les Chinoises ont un niveau d'études moins élevé et la plupart sont ouvrières. Beaucoup d'entre elles rechignent à révéler leur problème de santé (diabète) à leurs collègues et à leur employeur. Certaines craignent de perdre leur emploi si leur maladie chronique est connue. Les aléas de la vie ont empêché certaines d'entre elles de gérer correctement leur maladie. Dans bien des cas, elles ont eu du mal à accéder aux établissements de soins, elles n'ont pas appris grand chose des spécialistes de la santé et elles avaient peu de ressources leur permettant de comprendre leur état. Ces questions complexes ajoutées au fardeau de vivre avec une maladie chronique n'ont pas toujours été reconnues par les spécialistes de la santé, dont les interactions avec les immigrantes ne sont pas structurées pour révéler le contexte social de la maladie de l'immigrante.

Data from a comparative ethnographic study were examined to define factors that influence the management of illness among Euro-Canadian and first-generation Chinese women in the Canadian labour force. Compared with Euro-Canadians, Chinese women had a lower level of education, and more of them held blue collar jobs. Many of them had reservations about disclosing their chronic health problem (diabetes) to coworkers and employers, some fearing job loss if this information was revealed. Life circumstances prevented some of these individuals from properly managing their illness. In many cases they had difficulty gaining access to health facilities, learned little from health professionals, and had few resources to help them understand their condition. These complex issues that add to the burden of living with a chronic illness are not always recognized by health professionals, whose interactions with immigrant women are not structured to reveal the social context of the patient's illness.

It has invaded me. It has affected my whole life... It destroyed all my views in life, my attitudes, my goals, my aspirations, everything is affected by it. (Anderson, 1987-1989).

Regardless of the cultures from which we come and the social context of our lives, the diagnosis of a chronic illness can cut to the quick of our existence – as this woman tells us – “It destroyed all my views in life.” The news that one has a chronic illness is even more devastating when one is faced with eking out a meagre existence in a labour market where one has marginal status. The daily struggle to make ends meet may well take precedence over attending to

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the demands of a chronic illness. This is the experience of many who immigrate to Canada in search of a better life.

In recent years there has been a marked increase in the numbers of immigrants to Canada coming from different countries. In 1988 and 1989, for example, Hong Kong and India were among the leading source countries of landed immigrants (Canada Employment and Immigration, 1990). While those who migrate usually do so in search of a better life, the process of uprooting from one's home country and reestablishing roots in another often disrupts the social fabric of life and brings hardships. These difficulties are exacerbated when the language and culture of the host country are different from those to which one has been accustomed.

About 50% of immigrants to Canada are women (Canada, Employment and Immigration 1986). Although some are of comfortable means, a significant number of unskilled women are forced into the Canadian labour market out of economic necessity. Our data from a more recent study with randomly selected subjects revealed that about one-third of Chinese women and only three percent of Euro-Canadian women were unskilled (Anderson, 1990-91). Furthermore, some well educated women are unable to obtain jobs at levels similar to what they had in their home countries. Their qualifications are often not recognized in Canada and, for a number of reasons, they have difficulty acquiring the training that would allow them mobility in the labour market. For some women being in the paid work force does not exempt them from housework and childcare responsibilities; they therefore have little time for language and skill training (Anderson & Lynam, 1987). Gannage (1986) observed that the "double day of labour at work and at home made it difficult for immigrant women to obtain the language training that their male counterparts were able to obtain" (p. 196). Many women are therefore trapped in low paying, unskilled jobs, with no hope of mobility in the work force.

McGowan (1982) revealed that nearly one-third of all immigrant women were located in the most poorly paid sectors of the Canadian labour force, compared to only one-fifth of Canadian women and one-sixth of Canadian men. Minimum wage legislation usually did not apply or was not enforced in these jobs, and employer abuses of employees were common (p. 5). The conditions under which some immigrant women in North America live and work are not unlike those described by Brettell and Simon (1986) in the international context: subject to the triple discrimination of sex, birthplace, and class, they occupy the lowest levels in the labour market hierarchy, and have little security with few benefits (p. 10).

The conditions under which immigrant women live and work can have profound effects on their health. Bryan, Dadzie and Scafe (1985) stated that

black women in Britain tolerated the lowest paid jobs with poor working conditions, and dealt with a disproportionately high share of health hazards in the workplace (p. 91). Similarly, Bolaria (1988a) has noted that in Canada the jobs that immigrants are able to get expose them to numerous health hazards. When these workers must also deal with a chronic illness their difficulties are compounded.

Based on ethnographic data obtained from women living with diabetes (Anderson, 1987-1989), we argue that a woman's position in the labour force and the conditions under which she works can be major deterrents to the appropriate management of illness. We also argue that this is not always recognized by health professionals, whose interactions with the women are not structured to inform them of the social context of illness. In addition, the health care system often fails to accommodate the needs of non-English speaking women. It is not our intent to provide a detailed ethnographic report here, nor do we intend to focus upon diabetes as a disease category. Rather, we draw upon ethnographic materials to show that a woman's position in the labour force influences her ongoing management of a chronic illness. Women with diabetes were selected for this study only insofar as this disease requires ongoing management.

We need to go beyond the examination of culture to forward an analytic perspective for making sense of women's situation in the work force. While the discourse on culture gives us a window into understanding the meanings of illness, it does not adequately address issues that shape the experiencing of illness. Neither does an analysis of gender relations by itself provide an adequate explanatory framework for the difficulties immigrant women face. Carby (1982) pointed out that it is not just the institution of patriarchy that needs to be addressed to analyze the situation of black women; they are also subject to the oppression of class and race. She further argued that "racism ensures that black men do not have the same relations to patriarchal/capitalist hierarchies as white men" (p. 212-213). We believe that these comments are also relevant to other women of colour. In order to define the context of immigrant women's experiences feminist theory must be reformulated to address the issues of class and race. We attempt to use such a framework to analyze the experiences of those coming from poorer nations in particular, with their history of colonialism and oppression.

In earlier papers (Anderson, 1991a; Anderson, Blue & Lau, 1991), we explicated the process of life restructuring that occurs with chronic illness. Anderson, et al. (1991) suggested that Euro-Canadian women, fluent in English, were better prepared for jobs in the Canadian labour market. This enabled them to restructure their lives to deal with chronic illness. On the other hand, non-English speaking immigrant women in the lower echelons of

the work force had more difficulty finding jobs that would allow them to attend to their illness. In the current paper we deal explicitly with how the process of migration and the status of "immigrant woman" structure life experiences, and suggest directions for nursing to consider for the competent care of people from all ethno-cultural groups.

### ***Theoretical and methodological perspective of research***

The research we present is grounded in a feminist epistemology. According to Campbell & Bunting (1991), *"Epistemology is a theory of knowledge. Epistemology guides methodology, because epistemology concerns the questions of what can be known and who can be knower"* (p. 4). In a feminist approach, women are seen as a legitimate source of knowledge, and as experts on their own lives – women's experiences become the subject of investigation. It is critical and activist in its effort to improve the lives of women and all persons (Campbell & Bunting, 1991, pp. 6-7). In keeping with the perspective derived from Black feminism, we view feminism "as a process of self-conscious struggle that empowers women and men to actualize a humanist vision of community" (Collins, 1990, p. 39). In addition, we draw upon the method of institutional ethnography as explicated by Smith (1987) as a way of doing research. This approach allows us to give voice to the experiences of women, and analyze them within the broader social context. According to Smith:

The idea of an institutional ethnography emphasizes that the inquiry is one of discovering "how things work," "how they are actually put together." The notion of an ethnography lays stress on the project of being faithful to the actualities of social organization and relations. In contrast to research practices beginning with the concepts or theories of sociological discourse, the methods of this feminist sociology begin in an actual situation and explore the actual relations that organize it (pp. 147-148).

The aim of this method is "to explicate the actual social processes and practices organizing people's everyday experience from a standpoint in the everyday world" (Smith, 1987, p. 151). She emphasized that "inquiry starts with the knower... Activities, feelings, experiences, hook her into extended social relations linking her activities to those of other people and in ways beyond her knowing" (Smith, 1992, p. 91). When the experience of illness is viewed from this perspective, it cannot be teased apart from other aspects of a woman's daily life: getting and keeping a job; taking care of small children; cooking the dinner; doing the laundry; providing comfort and support to her partner and other family members; trying to make ends meet; and all the other activities of daily living. Illness becomes yet another thread woven into



the tapestry of her life. It influences, and is influenced by all ongoing social interactions, including those with health care providers.

Within the framework of institutional ethnography we can also extend our inquiry to the wider social relations that organize a woman's experience. For example, it allows us to locate this experience within the context of colonial oppression, and analyze how class and race oppression are perpetuated in a society where many of those who are from the poorer nations of the world are relegated to the lower echelons of the work force with no hope of upward mobility.

In qualitative research, especially research from a feminist perspective, the interviewer is aware that she is very much a part of the process of the social construction of knowledge. That is, although one's assumptions are explicit from the outset, inherent in the process of interviewing is the inter-subjective construction of meaning. Oakley (1981) wrote convincingly of the distinct differences between interviewing from a masculine paradigm and women interviewing women from a feminist paradigm. It became apparent to her that finding out about people through interviewing was best achieved when a non-hierarchical relationship existed between interviewer and interviewee, and when the interviewer was prepared to invest her personal identity in the relationship (p. 41). The interviewee, therefore, is not treated as the objectified other who is there to answer the researcher's questions. Nor are data treated as objective facts about the other, that are independent of the interpretive scheme of the researcher. Rather, there is a process of reciprocity between interviewer and interviewee (Anderson 1991b). Verification of interpretations of the data is an important aspect of this type of research.

### *Research Questions*

The questions we address are as follows: What are the illness experiences of women? How is illness managed on a day-to-day basis? What are the circumstances in women's lives that influence the management of illness?

### **Method**

To elucidate the special circumstances of the lives of immigrant women who have a chronic illness, we focus here on the findings from a recent ethnographic study with Chinese and Euro-Canadian women living with diabetes (Anderson, 1987-1989). We attempt to chart the course of illness over time, and identify the contextual features of everyday life that shape the experience and management of illness.

A letter (available in English and Chinese) explaining this study was given to women from a number of sources, including physician's offices, the Canadian Diabetes Association, and ethnocultural organizations. Some participants also invited their friends to take part. This approach to recruiting women is acceptable in qualitative research, where participants are selected on the basis of their ability to speak to the phenomenon in question. We contacted all interested women to answer their questions, explain the study in more detail, and inform them of their rights as a participant in the study. All participants signed a consent form which was available in Chinese for those who did not speak English or preferred to sign the Chinese version of the consent form.

Study participants included fifteen Cantonese-speaking Chinese women (two also spoke English) who were first generation immigrants to Canada, and 15 English speaking Euro-Canadian women, 13 of whom were born in Canada, and 2 of whom had lived in Canada for more than 12 years.

Although we had intended to match Euro-Canadian and Chinese women on the basis of education and occupation, this was not possible. Thus, the two groups were not similar in these respects. This difference between Chinese and Euro-Canadian populations of women also existed in a sample that we randomly selected from hospital clinics for a more recent study (Anderson, 1990-91). This perhaps speaks to the fact that a disproportionate number of immigrant women are in the lower echelons of the work force (McGowan, 1982). All the Euro-Canadian women, but less than 10% of the Chinese women had a minimum of Grade 11 education. All the Euro-Canadian women who worked outside the home were employed in professional/white collar occupations; only one Chinese woman was likewise employed. Most of the Chinese women in the labour force were in unskilled or skilled blue collar occupations.

The study lasted for two years, with data collection occurring for approximately one year. Two or three in-depth one-hour interviews were conducted with each woman during this time. A set of "trigger questions" pertaining to the areas, as outlined above, (e.g., women's experiences of illness, how illness was managed) were used to initiate the discussions with women. However, in this type of guided conversation questions are generated in the context of the interview, and the interviews are flexible enough to allow people to tell about their experiences from their own perspective.

Interviews with the Chinese women were conducted by a Cantonese-speaking research assistant in the women's homes. Not only did women discuss their beliefs about illness, they also spoke of their experiences in the

workplace and the process of seeking help from health professionals. They described the conditions of their work, and the ups and downs of everyday life that had a bearing on illness management. The interviews were then translated into English, and transcribed verbatim by a typist.

Data collection and analysis proceeded concurrently. As we collected and reviewed the data, women were asked to clarify points that were unclear to us. The data were systematically analyzed to identify conceptual themes. In a subsequent interview, women were able to validate our emergent interpretations to ensure that they were congruent with what they had intended. A further step in the process of analysis was to synthesize the conceptual themes into a coherent account of the participants' experiences of illness.

### *Illness in social and clinical contexts*

***The dilemma of managing a chronic illness in the workplace.*** Health professionals may take it for granted that a woman diagnosed with a chronic illness will reorganize her life to comply with the requirements of treatment. Not all women will find this possible. There are often pragmatic limitations to illness management. We found, for example, that the fear of losing their jobs led some women to keep their diabetes a secret from coworkers and employers: 36% of the Euro-Canadian women, and 67% of the Chinese women who worked outside of the home had reservations about disclosing diabetes in the workplace. For one Chinese woman illness was a private affair that did not warrant discussion with others:

If you have sickness, you don't want to tell everyone in the world about it. You know about it, and you take care of it, and you manage it and live with it. It's a very individual thing. No one can help you with it, so why talk about it?

While some women may have had reservations about discussing their diabetes, none had the fears of the working-class Chinese women. Sixty-seven percent (4/6) of the Chinese women employed in the lower echelons of the work force, feared that if coworkers and employers found out about their diabetes they could be fired from their jobs. Their fears of being fired were grounded in their knowledge that they were without job security.

We draw here upon the voices of Chinese women in the lower echelons of the work force to make visible the collective experiences of women in similar circumstances. When asked if people in the workplace knew about her diabetes, this is what one woman had to say:

Absolutely nobody knows. I would not tell anybody. If I say that I have diabetes, they would not hire me, they would fire me... If you don't plan to work it's okay, or if you are not working, it's okay. If you are working the employer could discriminate against you, and it's very troublesome to have diabetes....

They are very cautious about people with diabetes. They do not trust their work ability. When an employer hires somebody to work, they do not want to hire somebody with illness, especially chronic illness. For example, for diabetes, they would be afraid that you would faint or go into shock suddenly at work. So they would not hire you. Even I am on insulin injection, they would not trust me, so that's why I would not say anything (see also, Anderson, 1990).

While what this woman said could reflect a conception of diabetes as a highly stigmatized disease, it seems that pragmatic considerations about everyday life were foremost in her mind. As this woman tells us, "If you don't plan to work, it's okay." The real concern was that she would be replaced by someone who is seen by the employer as more capable.

The majority of the Euro-Canadian women felt at ease talking with employers and coworkers about the requirements of their illness, and organizing their time schedules to accommodate their special needs, as this woman's account suggests:

I distinctly remember having a discussion with my employer and his associate regarding meetings that were happening at lunch-time, and I told them specifically, I just explained, "I'm diabetic and I am going to have to be able to eat at noon, otherwise I can run into trouble." Basically that's all I said, and they said, "Fine, don't worry about it. We'll take a break for lunch first or we'll..." you know, they were willing to accommodate me and didn't see it as a big obstacle.

A woman's willingness to disclose her illness in the work setting could be related to her ethnicity, but it is more plausibly due to her position in the labour force and sense of job security. Euro-Canadian women who felt vulnerable in the workplace were also hesitant to discuss their illness until they had a sense of how employers and coworkers would respond. Chinese women who felt their jobs were more secure saw the sharing of information about illness as important. This is reflected in one woman's comment:

He [her boss] knows I have diabetes. *This is not a secretive thing. This should be told to the boss so he would know the signs and symptoms.*



One Chinese woman who owned her own restaurant felt no need to keep her illness a secret. Instead, she alerted her employees to her special dietary needs, so that her meals could be prepared accordingly. Feelings of vulnerability, powerlessness and marginality in the labour force were major deterrents to open discussion of one's illness, and this applied whether a woman was Chinese or Euro-Canadian. That more Chinese than Euro-Canadian women felt vulnerable in discussing their chronic illness speaks to the position of immigrant women in the labour market. They could not risk losing their jobs, as few employment options were open to them and they needed the income to survive.

Women who were reluctant to discuss their illness with employers and coworkers had to manage as if they had no special needs. In an effort to keep the information confidential, some were hesitant to monitor their blood sugar on the job or follow dietary regimens. Keeping diabetes a secret posed an outright hazard to one woman who worked in an area where, had she fainted, she would have been injured or killed. Although women feared that if they had a low blood sugar in the workplace no one would know how to help them, they feared the consequences of disclosing their illness even more.

***Seeking help: the dilemma for immigrant women.*** Immigrant women also had difficulties in their encounters with health professionals, and were unable to obtain the services they needed to mitigate the suffering caused by chronic illness. The data suggest that not all women felt able to express their concerns about illness to health professionals, whom they felt controlled the agenda in their interactions. Regardless of which health professional the women saw, they perceived that the medical management of diabetes often took precedence over the concerns of everyday life, even when these were paramount to the management of illness. The following quotation from one Chinese woman informs us that, although she and the physician spoke a common language, she did not feel free to question or express her concerns:

I seldom ask questions. Usually, if I ask or say anything I get scolded by the doctor. Actually, before even I ask the questions I am scolded by the doctor already. I don't have a chance to ask questions.... Every time he treated me like a kid, because he always scolded me, 'now don't eat this, and follow this, and be good'... He always says if you follow my instructions you will not end up like this. He's been saying the same thing over the years, and there is nothing new to say.

This "dialogue" with the physician indicates that, in this instance, the medical discourse was firmly embedded within a paradigm of caregiving where the doctor prescribed and the patient listened.

Not only was there no opportunity for some women to address the circumstances of their lives that influenced how they managed illness, some left the clinical encounter without a clear understanding of the biomedical management of diabetes. The following exchange highlights this:

*Woman:* With the injections, I often have episodes of feeling cold and shivering.

*Interviewer:* Did your doctor tell you why you are feeling this?

*Woman:* No. I told the doctor about this. He just listened but he didn't say anything. He has explanation for it, and I don't understand.... I just don't understand it.

Although some Euro-Canadian women encountered difficulties in their interactions with health professionals, they had access to such resources as libraries and support groups. Immigrant women with limited English skills had fewer resources to access.

A further problem that affected help-seeking patterns for immigrant women is that the delivery of health services was not geared to people who lacked flexible work schedules. Since, during the study period, all hospital clinics in the study area operated during the daytime, women who worked outside the home had to take time off from work to attend the clinic (End-note 2). This meant loss of income for those women who received pay for the hours actually worked. Furthermore, given that women were reluctant to reveal their illness to employers, they were hesitant to request time to seek medical care.

Even when women were able to get to clinics, the lack of trained medical interpreter services was a barrier to receiving care. Non-English speaking immigrants were expected to find their own interpreters. When a family member filled this role, it meant that both the woman and the family member lost pay. Women in the lower echelons of the labour market were most likely to need an interpreter, but could least afford the loss of income for themselves and for their family members. All these circumstances combined to increase the burden of managing a chronic illness.

### *Making sense of immigrant women's situation*

Although, the situation of immigrant women to some extent mirrors that of other women, an analysis of gender relations alone does not adequately explain their situation. A woman's place in the lower echelons of the work force influences how her illness is managed in the workplace. While some Euro-Canadian women found that their work environment was not conducive to illness management, a disproportionate number of immigrant women

spoke to this issue. For the most part, the immigrant woman was in a less privileged position than women from the Canadian mainstream. Without job security, many were forced to conceal their chronic illness. This can have deleterious effects on health. For example, they were reluctant to test their blood sugar at work or to inform coworkers about the signs of low blood sugar.

Health professionals often are not attuned to the conditions under which working class immigrant women live, nor do they seem to recognize how these conditions shape the management of illness. To understand the immigrant woman's experience with chronic illness, we must locate it within the context of her history as a woman (usually a woman of colour), and as a foreigner in a host country whose health care system is geared to the needs of the dominant majority.

*Reflections on the category "immigrant woman".* The term "immigrant woman" in itself implies a set of social relations that are historically situated. We start from the premise that the category immigrant woman, as Ng (1986, p. 13) suggests, is socially produced through a set of class relations:

Historically, "immigrant women" are the product of capitalist development, which displaces segments of the population from their indigenous livelihood and draws them to centres of new industrial development where they are more and more tied to an economy based on profit making: a monetary economy. "Immigrant women" become a social entity only after the rise of the phenomenon of immigration, which in turn indicates a process whereby different labour supply systems are integrated into the world capitalist economy... and where there is an international division of labour.

Labour market requirements in Western nations determine immigration policies at any given time. For example, some women from ex-colonial societies now provide a pool of cheap labour from which domestic workers are recruited. As more women from the mainstream in Western capitalist nations participate in the upper sectors of the labour market, menial jobs and domestic work within the home are shifted to women from ex-colonial societies. As Bolaria (1988a) noted:

For many workers, coming to Canada is a chance to escape the poverty and unemployment of home and to earn a regular wage, however menial and low-paying the available jobs might be. Their economic needs thus make them susceptible to exploitation. A labour force composed mostly of women and racial minority workers can be hired cheaply (p. 442).

The woman from the dominant capitalist nation stands in a power relation to the woman from the ex-colonial society, an observation that is by no means new. As Carby (1982) has noted, "Both white feminist theory and practice have to recognize that white women stand in a power relation as oppressors of black women. This compromises any feminist theory and practice founded on the notion of simple equality" (p. 214). The relations of power permeate different sectors of the Canadian workplace, where the immigrant woman from a racial minority group, by virtue of the job she is able to obtain, often finds herself in a position subordinate to the Euro-Canadian woman from the mainstream.

This situation highlights the class and power relations between women from different social categories, and points to the need for an analytic perspective that addresses the immigrant woman's experience in relation to her class position in society and history of colonial oppression. In this regard, the struggle of an immigrant woman in the lower echelons of the work force differs significantly from that of women from the mainstream, and her plight is usually neglected in the constructions of feminist theories from a Western standpoint.

The experience of illness by immigrant women, who are probably in the lower echelons of the work force, cannot be subsumed under those of women from the mainstream, in the same way that the analysis of women's experiences, in general, cannot be subsumed under those of men (Anderson, Blue & Lau, 1991; Meininger, 1986). For one thing, the woman in the lower echelons of the work force does not have access to the resources that facilitate chronic illness management (e.g., flexibility in the workplace, and interpreter services in the health care system). This results in a management strategy unique to her life circumstances; a strategy that can be quite different from that used by a woman within the mainstream.

***The politics of health care.*** Health professionals may well detect a difference between immigrant women and middle class Euro-Canadian women in their styles of illness management. The Euro-Canadian woman who has all the resources at her disposal may be better able to adhere to prescribed treatment regimens. She may follow her diet conscientiously and attend carefully to the other requirements of diabetes management. When this happens, she may be seen as a "good patient" who "takes responsibility" for her care. Not only is this woman usually able to reorganize work schedules and access resources to help her, she and the health professionals who provide care to her, may share similar notions about what constitutes good management. For example, both may see, the principles of "self-care management" as desirable. This is not simply because the woman has absorbed the instructions of the health care provider, but because, as Anderson and some of her colleagues have noted



elsewhere (Anderson, Elfert & Lai, 1989), ideologies underlying health care practices reflect the institutionalized order. Patients and practitioners from the same ethnocultural and socioeconomic group have access to similar forms of thought. If a patient manages her own illness by adhering to the principles of self care management, it may have more to do with a societal perspective that values "responsibility for self" than with adherence to a value-free scientific body of knowledge. The immigrant woman who speaks little or no English is usually excluded from the forms of thought within the host culture. The labelling of such a woman as non compliant or failing to take responsibility for self-care has to be understood from her position outside the value system of the dominant culture.

In seeking explanations for a woman's seeming non compliance, health professionals might pay little attention to the mediating circumstances of her life – her work conditions, economic situation and lack of access to health care resources that would compound her distress and confound illness management. This inattentiveness to the complex nexus in which illness is embedded arises from the decontextualization of illness and its management and an individualized view of illness which reduces it to a biomedical phenomenon. The practitioner interacts with the patient to elicit precise information pertaining to the disease, and develops a set of instructions for illness management. Whether or not the patient follows the instructions is seen as an individual matter that rests solely with the patient.

### **Implications for Nursing**

In the twenty-first century the emergence of a feminist scholarship in nursing could allow nurses to provide more compassionate care to people from different ethnocultural groups. This approach would direct us to examine the clients' cultures (and reflect upon our own culture), take the subjective experiences of individuals as the starting point of our analysis, and hold up to scrutiny the social, political and economic processes, including the history of imperialism and oppression, that have shaped – and continue to shape – the lives of many. Ethnicity, per se, may not be the deciding factor in how one experiences and manages an illness, but it cannot escape our attention that a disproportionate number of people from racial minority groups are situated in the lower echelons of the work force. Therefore, it is not their ethnicity but their history of colonialism and oppression that has shaped their subjective experiences. In the current study, women related that the conditions of their work had a profound influence on their health and how they managed a chronic illness. A reflexive feminist perspective demands that we not treat these inequalities as a fact of life, but respond to them in our practice with a new social consciousness, and actively seek ways of improving the human condition.

In other words, knowledge of the life circumstances of immigrant women needs to be utilized on a day-to-day basis in clinical practice. For example, behaviours that could be construed as non-compliance have to be reexamined in light of the conditions of the client's life. The label *non-compliant* infers that the client is at fault, or has chosen not to follow the biomedical model of illness management. For the immigrant woman, however, it may not be her choice but the conditions of life that structure the ways in which she manages her illness.

Analysis and change at the level of interaction with the individual will not be enough to address all pertinent issues related to the care of immigrant women. Issues in the organization like the organization of health care services, like the inappropriate hours when clinics are held, and the lack of adequate interpreter services, must also be analyzed and changed. This means that nurses must be prepared to identify inequalities and work toward influencing social and health policy decisions. The clinical practitioner is well placed to identify inequalities, and the nurse researcher can use findings to influence policy. Together they can bring about change, not necessarily just in the organization of health clinics, but possibly also in the larger societal context. Once we recognize that health and illness are socially produced, it is obvious that the boundaries of nursing should expand to identify and address social and political issues. We should not accept social injustice as a given; instead, we should accept the challenge to work toward social justice for all people.

### Summary

To analyze the immigrant woman's situation, and especially the immigrant woman of colour from an ex-colonial society, one must first recognize the context of her experiences. Yet, as Lugones and Spelman (1983) wrote, since the voices of women of colour have been excluded from the feminist discourse, immigrant women have seldom been heard.

The realities of poverty and marginality may be quite foreign to middle class health professionals schooled within the framework of western biomedicine. Therefore, perceptions of health professionals may differ markedly from those of the immigrant woman.

When we recognize the problems that women face as located within the historical, sociopolitical and economic contexts, we will begin to direct attention to the political arena to bring about social justice through legislation that will empower the powerless, and guarantee the rights of the underprivileged and oppressed. It is only then that immigrant women will become partners in the societies in which they toil.

### Endnotes

1. We have deliberately avoided the use of the term "developing nations." The terms "developed" and "developing," we believe, reflect a Western notion of what constitutes "development." "Western" is here taken to include European societies under prewar British and postwar American hegemonic leadership." (Ong, 1988: 90). As Ong points out, "neo-colonial preoccupations continue to haunt Western perceptions of ex-colonial societies... [it is suggested that] well known feminist studies on women in ex-colonial societies have not escaped this hegemonic world view" (p. 80).
2. Some evening diabetes clinics are now available in the study area.

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# **Finding Meaning in Chronic Illness as the Key to Self-Care**

**Cynthia Baker and Phyllis Noerager Stern**

Chez la personne ayant une maladie chronique, l'autosoin est une composante des soins qui en assure l'efficacité. Cependant, plusieurs personnes sont réticents à adopter les comportements d'autosoin. Le but de cette recherche qualitative est de décrire comment les personnes souffrant d'une maladie chronique, dont les symptômes peuvent être contrôlés par le traitement médical, développent la volonté de prendre en charge leurs soins. La méthode inductive pour l'élaboration d'une théorie a été utilisée. Un échantillon sélectif de douze personnes souffrant d'une maladie chronique et neuf infirmières qui les visitaient à domicile a été interviewé. Les résultats indiquent que le processus clé pour la prise en charge des soins est le sens donné à la maladie. Ce processus implique une acceptation de la maladie chronique et une vision de ses effets sur la vie de la personne. La découverte de cette signification lui permet d'assimiler les informations concernant l'autosoin et de percevoir qu'elle a la capacité d'influencer son état de santé.

Self-care is an important element in the successful management of a long-term illness. However, people with chronic illnesses are often reluctant to adopt self-care behaviors. The purpose of this grounded theory study was to investigate the evolution of a readiness to self-manage a nonfatal chronic illness. A purposive sample of twelve individuals with a nonfatal illness whose course can be controlled by treatment were interviewed. In addition, the primary nurse caring for each informant at home was also interviewed. The findings indicate that the key process in self-care readiness was finding meaning in chronic illness. This process involved assenting to the illness and reframing its implications positively. It allowed informants to make sense of self-care teaching and to perceive themselves as self-care agents having some control over their illness course.

This grounded-theory study investigated the evolution of readiness to self-manage a nonfatal chronic illness. Its purpose was to inductively derive a conceptual framework to describe the processes involved in self-care readiness and explain their development among adults with a chronic illness whose course can be controlled through a treatment regimen.

Broadly speaking, self-care refers to the activities that individuals initiate and perform on their own behalf to maintain life, health, and well-being (Orem, 1985). It is especially important for persons with long-term illnesses because they look after themselves at home much of the time (Corbin & Strauss, 1988). Responsibility for managing the symptoms of a chronic illness and administering the treatment regimen often falls on the person who is

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sick, rather than on health-care professionals. However, many people with a chronic disorder hold the traditional sick-role expectation that the treatment regimen will be carried out by health-care professionals. Their estimate of the amount of care they should receive from others often is higher than that of community nurses visiting them at home (Van Agthoven & Plomp, 1989).

The recognition among nurses that the nature of clients' participation is the key element in successful health promotion, health maintenance, illness prevention, and illness management has created an interest in the concept of self-care. Various approaches to self-care have been developed and are being used in nursing (Richardson, 1991). Despite differences in their assumptions, the models agree that readiness for self-care is necessary for its adoption. What readiness for self-care involves and how it develops are poorly understood.

The symbolic interactionist school of sociology guided the assumptions underlying this study. Symbolic interactionism focuses on the meanings of events to people, and the symbols they use to convey that meaning. Blumer (1969) noted that human behavior results from "a vast interpretive process in which people, singly and collectively, guide themselves by defining objects, events and situations they encounter" (p. 132). For people to function in groups, meanings must be shared, and this is accomplished through language and socialization (Chenitz & Swanson, 1986). Because meanings are continually being revised in social interaction, the symbolic interactionist perspective is dynamic and process driven, rather than structural and static. It focuses on psychosocial processes that exist either within the individual or among groups of individuals.

At the outset of a grounded-theory study, the research question is broad. As data collection and analysis progress the investigator's focus sharpens and the question narrows (Glaser & Strauss, 1967). In this study, the following research question emerged: How does self-care readiness develop among persons with a chronic, non-fatal physical illness whose course can be controlled by treatment?

### **Literature Review**

Self-care is a complex concept with multiple meanings. Sometimes it is used to convey client independence from the formal health-care system. At other times, it refers to the performance of behaviors prescribed by health-care professionals. Nurses have tended to view self-care goals as derived mutually by the client and the health-care professional in interaction with one another (Gantz, 1990). Nursing models for understanding self-care behavior indicate that simply teaching clients about self-management of their chronic

illness does not necessarily lead to self-care behaviors (Utz, 1990), and that clients must be ready to use the self-care information they receive. For instance, Orem's self-care deficit theory of nursing pinpoints agency as the key factor in self-care behavior. Self-care agency is defined as the capabilities of individuals that enable them to engage in self-care (Orem, 1985), and involves a repertoire of actions that are set in motion by enabling power components such as motivation. In Steiger and Lipson's (1985) conceptual framework for self-care, motivation is identified as central to the adoption of self-care behaviors. The modeling and role-modeling theory of nursing developed by Erickson, Tomlin, and Swain (1983), postulates that self-care actions depend on a person's emotional ability to mobilize both internal, personal resources and external resources.

Studies of self-management of chronic illness have investigated variables related to self-care. A study of 558 insulin-treated diabetics found that a person's attitude was the most important determinant of self-care (Weerdt, Visser, Kik, & Van der Even, 1990). Chang, Ulman, Linn, Ware, and Kane (1985) investigated the factors that contributed the most to the intention of adhering to a treatment plan in a sample of 26 senior citizens. The researchers identified psychosocial care as the key component. The effectiveness of two models of self-care intervention for persons with arthritis was investigated in a pretest-posttest control-group experimental study. Decreases in perceived helplessness accompanied self-care behaviors, although which preceded which was undetermined (Goeppinger, Arthur, Baglioni, Brunk, & Brunner, 1989). Corbin and Strauss (1988) used the grounded-theory approach to study how people live with a wide spectrum of chronic illnesses. They found that effective management of the trajectory of a chronic illness requires a considerable amount of work, an important part of which involves people's ability to redefine their identity in such a way that they can accept the impact of their illness symptoms on their life. The findings of these studies suggest that clients' readiness for self-care is a prerequisite for using the health information given to them by health-care professionals.

It is unclear which factors are involved in the development of self-care readiness. Orem (1985), for example, considers foundational dispositions such as self-worth, the ability to make decisions, and the ability to learn as prerequisites to the power components in self-care agency. However, there is no one-to-one correspondence between individual foundational dispositions and power components, and their specific relationship to each other is not obvious. As a result, instruments developed to measure Orem's concept of self-care agency have selected different combinations of power components and foundational dispositions (Geden & Taylor, 1991; Hanson & Bickel, 1985; Kearney & Fischer, 1979; McBride, 1987; Riesch & Hauk, 1988). Client

participation in determining therapeutic objectives has been put forward as a possible determinant of self-care readiness, but findings have not been significant. Conway-Rutkowski (1982) examined the literature to investigate the hypothesis that there is a relationship between self-care and patient participation in the nursing process; she concluded that it could not be confirmed. Krouse and Roberts (1989) used an experimental design to examine whether individuals who participate in an actively negotiated process of decision making with the practitioner perceive that they have more control over their care and express greater agreement with the recommended treatment plan. Significant effects were found for an active negotiated style of interaction and perceived control, but not for agreement with the treatment plan.

In summary, readiness for self-care expressed as motivation, attitude, or internal resources has been identified as a significant factor underlying self-care behaviors. However, what makes a person ready to self-manage a chronic illness is poorly understood.

### **Method**

The grounded-theory method was selected for the study. This approach is rooted theoretically in symbolic interactionism, and its purpose is to explain a given psychosocial situation by identifying the core and subsidiary processes operating in it. The core process is the guiding principle underlying what is occurring in the situation and dominates the analysis because it links most of the other processes in an explanatory network. Therefore, grounded-theory is used to generate inductively based theoretical explanations of social and psychosocial processes.

Consistent with the grounded-theory approach, theoretical sampling was used in this study. Thus, data analysis and data collection were carried out simultaneously, and the evolving analysis drove the selection of respondents. Ultimately, informants were selected from three groups: individuals with a nonfatal chronic illness, community nurses caring for these informants, and nurses working with chronically ill patients in other settings.

The sampling process was initiated by interviewing twelve informants with a chronic illness who were being visited at home by nurses of the Extra Mural Hospital of New Brunswick. This hospital provides 24-hour services at home to patients who do not need round-the-clock care. Each informant had a nonfatal chronic illness whose course could be controlled by following a treatment regimen. Their medical problems included insulin-dependent diabetes, renal failure, cardiovascular diseases, and a recent colostomy for bowel cancer. In order to focus specifically on the effect of the chronic illness rather than the effect of aging, the informants chosen were under 65 years of



age. Their ages ranged from 18 to 65, and the modal age group was 40 to 49. Four were francophones and eight were anglophones; four were male and eight were female. The investigator is bilingual and conducted the interviews in the informants' first language.

Analysis of the data obtained from these informants led to further sampling. In order to triangulate by using different sources, each informant's primary nurse from the Extra Mural Hospital was interviewed. The nature of their interventions and their assessment of the informants' responses to their illness and self-care were elicited. In each case, the nurse's description of the client's responses to the illness and to self-care confirmed the account given by the client. Because three of the nurses were each caring for two informants, only nine nurses were interviewed.

At this point in the data-collection and analysis process, concepts were saturated and a conceptual framework emerged. Literature was then selectively sampled and five nurses who work with chronically ill patients in other settings (diabetic clinics and discharge planning) were interviewed. Processes previously observed were compared with those occurring in these situations. Finally, four of the original informants were contacted again to verify the framework.

As noted, following the grounded-theory approach, data collection and data analysis took place concurrently. An open-ended interview schedule was designed for the original interviews with the informants. Questions covered the history of their illness, the medical treatments and nursing care received, their social life, sick-role expectations, their self-care attitudes and behaviors. Some examples of questions asked concerning self-care are: "When you become aware of new symptoms or changes in old symptoms, what do you do about it? Are there things that you do for your health that weren't suggested by a health professional?" Other questions include: "Can you tell me about your treatment plan? Is anyone helping you follow the treatment plan? On the whole, how do you feel that you are managing with your illness?"

Interviews were conducted in informants' homes, lasted from one to two hours, and were tape-recorded. Another schedule was developed for the interviews with the primary nurses who were interviewed in their office. These interviews were also tape-recorded and lasted from one to two hours. Consistent with the method, interview schedules were not rigidly adhered to. Questions were altered and new questions were added as the ongoing analysis sharpened the focus of the study. The interviews with nurses in other settings and the follow-up interviews with the original informants were constructed from a general list of items to be covered.

The data analysis was based on the constant-comparative method. Early data were coded with words that described the action in the setting. As more information came in, codes were revised and the data were recoded. Categories were developed from the clustering of codes that seemed to fit together and were constantly compared with each other to ensure that they were mutually exclusive and covered the behavioral variations. Categories were then linked to form a tentative conceptual framework. As this was being developed, concepts were reviewed, discussed, and modified by colleagues in a grounded-theory seminar.

The emerging conceptual framework was delimited and integrated by memo writing and theoretical coding. Memos were used to record the theory as it developed step by step. Theoretical coding refers to the process of examining data in a theoretical way rather than in descriptive terms.

Before data collection was initiated, the study proposal was approved by the ethics committee at Dalhousie University. Informants were given a verbal and written explanation of the purpose of the study, and each signed a consent form. Anonymity was maintained.

### Findings

All nurses who were interviewed believed in the value of self-care and encouraged it. In contrast, all informants initially were reluctant to assume any part of the management of their illness. However, more than half of the informants reported that this had changed, and they now described themselves as self-care agents. A brief overview of the model of self-care readiness that emerged from the data will be provided first and then each of its processes will be described and illustrated with informants' comments (see Figure 1).

Nonaccommodation to chronic illness was the starting point for the development of self-care readiness among informants. This nonaccommodation impeded their assimilation of self-care teachings. It was linked to their view of themselves as either incapacitated or recurrently sick, and therefore dependent on others. The core process mobilizing the evolution of self-care readiness was labelled "finding symbolic meaning in chronic illness." This process was two-dimensional, involving assenting to the chronic illness and reframing its implications positively. These dimensions interpenetrated one another and unfolded together. All informants who were committed to self-care found meaning in their illness but none of the informants who were reluctant to manage their illness themselves did so. Informants who saw themselves as self-care agents felt that they had some control over their illness and that they were normal despite it. They were able to make sense of their nurse's self-care messages.

### ***Nonaccommodation to the Illness***

Some informants experienced a dramatic onset of their illness, whereas for others it developed slowly and insidiously. At some point, regardless of how the illness began, informants recognized that it was not following the trajectory of the acute sicknesses they had had in the past. All responded by rejecting the unfamiliar illness pattern. They did this either by seeking a cure, by looking for scapegoats to blame for their situation, or by giving up on life. Many did all three, alternating between them.

Seeking a cure involved a refusal to accept that no medical cure for the illness was currently available. One example of this was a highly educated individual who developed insulin-dependent diabetes. Despite receiving extensive teaching about his illness, he was convinced that taking insulin was a temporary measure to restore pancreatic function. Some informants spent years going from one doctor to another searching for cures for their chronic condition, for symptoms arising from poor self-management of the condition, and for problems arising from treatments, already obtained. One woman who described such a process called herself a "believer in medicine."

When scapegoating, informants rejected their illness with anger and bitterness and looked for someone or something to blame it on. Common scapegoats were God and fate. One young man said, "I just look up and say, 'Why me, Lord?' My sister told me this joke. She said this guy looked up and said, 'Why me, Lord?' The heavens opened up and this voice said 'Because you piss me off.' I'm still waiting for that voice!"

A woman believed that she was destined by fate to experience vicissitudes in her life. She put it this way: "With my luck – I seem to have everything go wrong. Even when I was a kid, if anybody had problems it was me!"

Physicians were another scapegoat for feelings of resentment. "They're not gods" said one woman, expressing her frustration that they could always find a "name" for her health problems but couldn't "do anything about it." Another said, "You have to trust your doctors, but don't trust them to the point that you think they're going to fix you... prepare for the worst."

At times, informants who rejected their illness were so overwhelmed by feelings of futility that they gave up on life. "Look," said one man, "I was going to commit suicide the first time I got hold of a gun." A woman who said, "I drag myself around" described herself as an invalid and gave up going out: "I can't go too far from home because I have to use the bathroom about every half hour – I can't go anywhere." Another informant felt that his life was useless and described himself as being "just a wreck."

### *Finding Symbolic Meaning in the Illness*

Informants who became self-care agents no longer sought a cure, scapegoated, or gave up, but perceived chronicity positively. They found symbolic meaning in chronic illness by assenting to it on the one hand, and by reframing its meaning in their life on the other hand.

Informants who assented to their illness acknowledged its existence, accepted that it was long term, and recognized that it was not currently curable. For instance, one woman who had spent years seeking a cure finally told a physician who had just prescribed a new series of diagnostic tests for her, "Please don't try to cure me any more." She explained this decision: "I don't want anyone to get the idea that I don't want to get better – I do – but I realized then that there's no cure available." For these informants, embracing the painful reality of their illness seemed to diminish its sting. For instance, one woman with diabetes had become effective in managing the symptoms of the illness after years of rejecting the prescribed treatment regimen and poor blood-sugar control. She described diabetes as something that she would always have and said, "It's not too bad really. I'm used to it now and I take it day by day. I have a good life." Another who found his illness a terrible "shock" at first said that he had "adapted to it – I enjoy a professional life and a family life that permits me to live very well."

As informants assented to their illness, they reframed chronicity by reconstruing its implications in a positive way. One method they used, cognitive optimizing, has been identified by Forsyth, Delaney and Gresham (1984). In cognitive optimizing, informants compare themselves favorably with others. Implicit in the comparison is that by having the illness they have been spared something far worse. For example, one informant said, "A lot of others are much worse off than me. I find myself lucky when I see a cripple or, you know, somebody who is really sick."

Another method of finding something positive in the situation was to identify others with similar health problems who are living particularly effective and worthwhile lives. A woman spoke respectfully of a man who had a colostomy like herself. She noted that this man was always written up in the newspaper because of his active involvement in establishing a food bank. Similarly, a young informant with diabetes talked admiringly about a teenager she knows "who's been a diabetic for years and is the captain of the cheerleader squad."

Some informants found that the illness actually improved their life in some way. For instance, one man said that his illness had forced him to re-evaluate the quality of his life, and found that he needed to "live" rather than



simply “survive.” As a result, he said, he has learned to relax more and has a much happier relationship with his wife and children.

### *Making Sense of Self-Care*

Once informants found meaning in their illness, they were able to make sense of their nurse’s self-care teachings by tuning in, integrating, and incorporating these messages. In contrast, non-accommodation to the illness decreased receptivity to the promotion of self-care. One of the earliest models of communication, the Shannon-Weaver model, introduced the concept of “noise” (Shannon & Weaver, 1949). Noise refers to factors that influence or disturb messages while they are being transferred from the source to its destination. In a sense, seeking a cure, scapegoating, and giving up were “noise” because they led informants to tune out, fragment, and avoid self-care messages. The processes involved in making sense of self-care will be presented sequentially, although in reality they overlapped one another.

***Tuning in versus tuning out.*** In the first step toward making sense of self-care, the informant had to register self-care messages by actively listening to them. Finding meaning in the illness was accompanied by a movement from tuning out to tuning in self-care messages. This was illustrated well by the comments of one informant and his nurse, whose accounts corroborated one another’s. While rejecting his illness, the informant heard none of the self-care teaching he had received. He explained, “I was completely unconscious – I understood nothing.” His nurse said of this period, “Absolutely nothing went in – everything he was taught hit his ear and bounced right back out.” The nurse described how he came to hear what she was teaching him: “At a certain point he began telling me that he was looking at his life, readjusting his approach to living, and finding his life better. This is when he began to hear what I was saying.”

***Integrating versus fragmenting.*** Another aspect of making sense of self-care was integrating various strands of self-care messages together. Informants began to perceive the management of their illness as a whole. A comment by one woman who sees herself as a self-care agent illustrates this:

I’ve learned to control my illness – I follow the treatment now and I keep my weight down. I lost 18 pounds. I’ve been walking once a day, every day, at the same time. Because I’m looking after myself I don’t think that I’ll get worse.

Informants who were unable to accommodate to their illness sometimes adopted discrete aspects of the self-care messages they received but perceived them in a fragmented fashion. What was retained or dismissed varied considerably. For instance, one woman with a circulatory problem focused on doing

her own dressings for recurring leg ulcers but ignored teachings about life-style factors. The nurse commented, "It's not that she's ignorant or anything – she's a well versed person and what you tell her is nothing new." This informant had never abandoned her search for a cure. Although she had indeed heard the self-care messages, she discounted them. In contrast, a man who also had leg ulcers as a result of circulatory problems felt very hopeless and discouraged about the effect this was having on his life. He was completely unreceptive to self-care teachings related to the concrete care of the leg ulcers. However, he had registered information about life-style factors, and modified his diet and gave up smoking.

***Incorporating versus avoiding.*** The final step in acquiring the self-care message was finding a way to make the self-care behaviors part of the routine of life. This was difficult because all informants found something about self-care that was unpalatable to them. Resolution of the incorporation process usually involved discovering ways of making self-care behaviors easier. For instance, a diabetic was unable to give herself insulin. As she began to come to terms with her illness and to reframe it, she renewed her efforts to give herself insulin by establishing a ritual: "I never give myself insulin until I put the bottle back in the box, Never! I always keep the needle covered so I don't have to look at it. I just take the cover off at the end." For another diabetic informant who "loved to eat," incorporating the diet into her daily life was the real stumbling block until she found meaning in the illness. Then she was able to develop a number of strategies, such as buying a diabetic cookbook and making the same meal for her husband and herself. In case of an insulin reaction, she kept a type of candy bar that she disliked so that it would not tempt her otherwise. Nonaccommodation to the illness reduced informants' interest in finding ways to incorporate self-care behaviors.

### ***Defining Self as Agent***

Informants who did not find meaning in their illness saw themselves as either chronically incapacitated or, if their symptoms flared up and subsided, recurringly sick. Nonaccommodation prevented them from integrating the illness into their identity in a way that allowed them to see themselves as having some control over it and as being a normal person. In contrast, informants who found symbolic meaning in their illness not only began to make sense of self-care messages, they also began to see themselves as self-care agents. This included a growing belief in their ability to exercise some control over the course of the illness and a perception of themselves as normal rather than as sick or handicapped.

The feeling of control that was part of the informants' perception of themselves as a self-care agent involved a conviction that how they lived and

looked after themselves influenced the trajectory of the illness. Informants who felt in control directed their energies toward trying to develop a more effective life style and finding ways to manage the treatment regimen well. One respondent described this process as follows:

I try to create an environment for myself where I feel at ease, an environment where I feel well, because strong emotions affect my illness. I have also taken all sorts of measures to create this environment, a sauna to relax for instance. I don't think my health will deteriorate unless I choose a form of suicide, unless something happens in my life and I am no longer master of myself.

Informants who perceived themselves to be active in managing their illness also explicitly described themselves as normal. The feeling of normalcy incorporated the idea that although the illness was an integral part of them, it did not prevent them from adopting the social roles associated with their stage of life. A comment by an eighteen-year-old respondent illustrates this:

I'm independent and I don't expect to be waited on. At first Mum and Dad sort of went easy on me, but now they get at me just as much as they used to. And I'm comfortable with my friends now, and they don't force me, like "Oh come on you can have it." At McDonald's I'll eat a salad. Diabetics are just normal people who have to take an insulin shot.

### **Discussion**

The analysis indicates that readiness for self-care in chronic illness is a complex and dynamic process. How informants see themselves in relation to their illness appears to be a critical factor in their receptivity to self-care teachings. Lazarus and Folkman (1984) argue that people continuously appraise situations in terms of the potential impact on their well-being. A primary appraisal involves a judgment about whether an event creates an actual or potential harm or loss. A secondary appraisal concerns the options the person has for responding to the situation. Initially, informants appeared to have judged their illness as a harm/loss situation. Some responded by seeking a cure, which reflected a refusal to believe that their illness is chronic. Their reaction is consistent with the findings of previous studies. Whereas some individuals initially respond to the diagnosis of chronic illness with denial (Fredette, 1990; Matson & Brooks, 1977; Redman, 1993), others respond by scapegoating, giving up, anger, and despair; emotional reactions often associated with loss in general (Erickson, Tomlin, & Swain, 1983). It is interesting to note that the process of giving up that characterized some informants is similar to the reaction to loss described by Engel (1968). Both connote a sense of psychological impotence and a feeling that one is unable to cope.

Finding symbolic meaning in a chronic illness by accepting its reality and reframing its implications is no easy challenge, but some informants had done this. This process seems to underlie self-care readiness. It resulted in informants seeing themselves as normal and as having some control over their illness. It may therefore have altered their secondary appraisal of the situation by encouraging what Bandura (1977) refers to as efficacy expectancy, the belief that a person can produce a required outcome. It also appeared to foster what Bandura terms outcome expectancy, the belief that a given behavior will result in a particular outcome.

### **Limitations**

Some limitations of the study need to be mentioned. First, due to theoretical sampling, the findings cannot be generalized to other sample populations. However, Lincoln and Guba (1985) argue that the transferability of qualitative studies depends on the fit of the findings to other situations and is more the responsibility of the person wanting to transfer the findings. Second, the selection of informants was restricted to those with a chronic illness that could be managed through a medical-treatment regimen. The findings could differ in subjects with a terminal illness or multiple sclerosis, which may be difficult to control through medical treatment. As interviews were the principal method for collecting data, the findings depended on the truthfulness and accuracy of the informants.

In order to offset the limitations inherent in qualitative research, the field experience included interviews with nurses as well as patients. There was peer examination of codes and categories. A reflexive journal was kept in which memos were written about evolving hypotheses. A clear decision trail was maintained, and informants validated the analysis. Nonetheless, it is proposed that a future prospective study of newly diagnosed chronically ill individuals would help to verify the temporal relationship between finding symbolic meaning and self-care readiness.

### **Implications**

Gadow (1980) has proposed that nurses be existential advocates who participate with their patients in determining the personal meaning that the experience of illness, suffering, or dying has for those persons. The framework that emerged in this study argues for such a relationship-oriented approach to self-care teaching. An important implication of this study for nursing practice is that nurses should attend to the symbolic meaning that the illness has for the client in order to promote self-care. It suggests that by helping their clients to come to terms with chronicity and reframe the illness, nurses are more likely to be effective in teaching them to be self-care agents.



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# Le Caring : Vers une conception interactionniste

Cécile Bouchard et Brenda Kean Dutil

The concept of caring evokes many images and experiences, interpersonal caring, professional caring, caring for and being cared for. In this article, we explore several conceptualizations of caring as proposed by significant philosophers and nurse scientists. The philosophical perspective of caring can be presented by two basic assertions: "Being is relating" and "Being is caring". Conceptions of caring advanced by nurse scientists can be grouped according to four epistemological models: ethnographics, humanist, feminist and phenomenological.

We also present a conceptual model of caring inspired by symbolic interactionist theory. This model describes and explains caring as a psychosocial relational process based on interaction, significant or meaning, interpretation and action. These notions help us understand this essential human phenomenon situated at the heart of the nursing profession.

Le concept du *caring* évoque de nombreuses images et expériences, la prévenance dans les relations interpersonnelles, la bienveillance professionnelle, le fait de prendre soin des autres et d'être soigné. Nous examinons dans cet article diverses conceptions des soins, telles qu'elles sont proposées par des philosophes de renom et des chercheurs en sciences infirmières. La perspective philosophique des soins est présentée selon deux affirmations de base : «être, c'est entretenir des relations» et «être, c'est soigner». Les diverses conceptions des soins avancées par les chercheurs en sciences infirmières se répartissent en quatre modèles épistémologiques : ethnographique, humaniste, féministe et phénoménologique.

Nous présentons également un modèle conceptuel de soins inspiré d'une théorie symbolique interactive. Ce modèle décrit et explique les soins en tant que processus relationnel psychosocial fondé sur l'interaction, le signifiant ou le sens, l'interprétation et l'action. Ces notions nous permettent de comprendre ce phénomène humain essentiel et qui est au coeur des sciences infirmières.

Qui n'a pas le souvenir d'une personne qui lui a procuré tendresse et réconfort? D'une présence rassurante dans certains moments difficiles? Et qui parmi nous, infirmières et infirmiers, ne vit pas à chaque jour des moments d'intimité avec des bénéficiaires, moments souvent arrachés au «tapis roulant» des tâches techniques et bureaucratiques? Chaque geste de tendresse, de soutien, d'intimité et de sollicitude témoigne d'un phénomène que les auteures d'expression anglaise nomment le *caring*. Ce mot englobe différents concepts, tels que l'expérience de soin personnel ou professionnel, l'expérience de prendre soin des autres et l'expérience de recevoir des soins. Autant que possible, nous emploieront des expressions françaises pour le désigner. Mais afin d'éviter l'emploi d'expressions peu élégantes telles «besoin de soin», nous utiliserons fréquemment le mot *caring*.

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Le *caring*, phénomène à la fois omniprésent et fragile dans la vie personnelle et professionnelle, réclame notre attention. Nous explorerons ici quelques conceptions du *caring* proposées par des philosophes et des infirmières qui ont contribué à faire comprendre ce phénomène. Nous présenterons ensuite un modèle conceptuel du *caring* basé sur l'interactionnisme symbolique. Nous espérons que cette réflexion renouvellera l'intérêt pour le *caring* en tant qu'expérience interactionnelle de soins.

### **Fondements philosophiques de la notion de caring**

Plusieurs philosophes ont cherché à définir l'essence du phénomène du *caring*. Nous prendrons en considération ceux et celles qui ont eu une influence prédominante sur les infirmières ayant cherché à situer le *caring* dans le contexte des soins infirmiers, afin de comprendre à quel héritage intellectuel ont puisé ces dernières.

Pour le philosophe allemand Heidegger (1927), le souci (*caring*) exprime le caractère ultime de l'être humain, de sorte que les différentes façons d'être au monde sont toutes des manifestations de ce souci. Pour lui, ne pas se soucier des autres conduirait à la perte de son être, alors que le souci serait le moyen pour le retrouver. Soulignons que Benner et Wrubel (1989) ont adopté la pensée de Heidegger pour fonder leur approche du *caring*.

Marcel (1961), philosophe français, a aussi marqué la conception du *caring* avec ses notions de «présence» et de «mystère». Marcel (1959) a défini ainsi la présence : une personne «est capable d'être avec moi, avec la totalité de mon être, quand j'en ai besoin». Plutôt que de se placer à l'extérieur d'un phénomène, la personne ne doit pas oublier qu'elle est concernée, touchée et incluse dans celui-ci. Selon Marcel, la recherche d'une réponse à la question existentielle «qu'est-ce que l'être humain?» implique un processus de co-présence où il s'agit de se rendre présent à une réalité, à un phénomène à dévoiler, qui ne sera jamais entièrement saisissable parce qu'il comporte une part de mystère.

Buber (1959), théologien israélien d'origine autrichienne, présente la relation dialogique entre un «je» et un «tu» comme le lieu à l'intérieur duquel se réalise la co-présence et l'authenticité. Pour lui, cette relation constitue le fondement de l'humanité; l'être humain n'atteint à l'humanité qu'au sein de l'expérience du dialogue dans l'espace interhumain. Bien qu'il n'ait pas spécifiquement parlé du *caring*, cet auteur a influencé les infirmières parce qu'elles ont trouvé chez lui la description et l'explication du contexte relationnel dans lequel le *caring* se produit.



May (1971), psychologue existentialiste américain, présente le *caring* comme état et comme action. En tant qu'état, il implique la reconnaissance de l'autre comme participant de la même humanité, ainsi que l'identification avec la souffrance ou la joie de cet autre. Il s'agit d'appréhender l'expérience de l'autre à partir de son point de vue à lui, à partir de ce qu'il ressent. Le *caring* est aussi une action en ce sens qu'il appelle à prendre des décisions et à agir pour celui qui a besoin d'aide, à agir à partir de ce qui est ressenti.

Mayeroff (1971), autre psychologue américain, conçoit le *caring* comme étant constitué de tout ce qui peut permettre la croissance et le développement de l'autre d'une façon non possessive. Il décrit huit aspects essentiels du *caring* (traduction des auteures):

1. La connaissance de soi et de l'autre.
2. L'alternance d'un cadre de référence restreint à un cadre de référence plus global afin de maintenir ou de modifier son propre comportement.
3. La patience, afin que l'autre puisse s'approprier à la relation.
4. L'honnêteté envers soi-même face aux besoins changeants de l'autre.
5. La confiance en la capacité de croissance de l'autre.
6. L'humilité de reconnaître que l'on puisse apprendre de l'autre.
7. La foi en relation avec l'engagement et l'implication.
8. Le courage d'affronter l'incertitude de l'inconnu.

Gilligan (1982), également psychologue américaine, s'est mise à l'écoute de l'expérience des femmes pour fonder une théorie du développement moral. Ainsi, l'expérience de *caring* des femmes fondera une éthique de la sollicitude définie comme «une préoccupation fondamentale du bien-être d'autrui».

Selon Noddings (1984), philosophe américaine, la sollicitude comme idéal éthique se construit dans la relation entre une personne qui se préoccupe d'une autre et une personne de qui l'on se préoccupe. En mettant l'accent sur «l'être avec les autres» comme caractéristique fondamentale de la sollicitude, Noddings et Gilligan réhabilitent l'expérience de *caring* des femmes et elles agrèent la position de Buber à l'effet que le *caring* s'effectue au sein d'une relation, qui constitue la base de notre humanité. Il s'agit d'une relation affective de réciprocité où la personne soignante accepte de porter en elle la personne soignée, de la sentir du dedans, en profondeur.

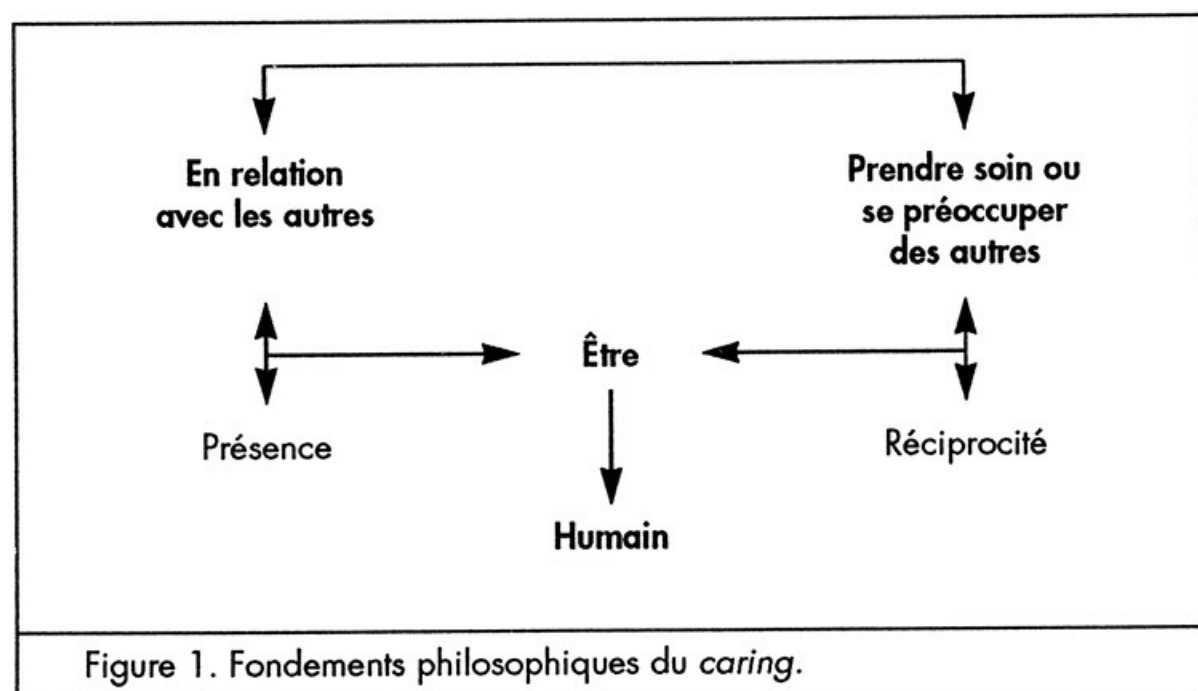
Si nous récapitulons les différentes positions, il ressort deux grands schèmes de pensée qui expriment le fondement ontologique de l'humanité, en d'autres termes, qui répondent à la question «qu'est-ce que l'être humain?».

Le premier peut être résumé comme suit : être, c'est être en relation avec les autres. L'être humain n'existe qu'en présence de l'autre. Le deuxième s'exprime ainsi : être, c'est prendre soin des autres. L'humain est humain parce qu'il se préoccupe et prend soin (care) des autres. Nous proposons de fondre ces deux positions en une seule : L'humain est un être en relation avec les autres, qui se préoccupe et prend soin des autres. Le *caring* est la façon d'être humain. Il se manifeste à l'intérieur d'une relation de co-présence et de réciprocité. La Figure 1 permet de visualiser cette synthèse des positions philosophiques.

On ne pourra jamais totalement répondre à cette question existentielle car le *caring* restera toujours en partie voilé, l'être humain étant en perpétuelle évolution. Le *caring* se dévoile et prend un sens différent selon la personne qui l'étudie. Au cours de la dernière décennie, ce sont les infirmières qui ont le plus contribué à l'exploration du *caring*, à partir de leur expérience de soins. Elles ont apporté à la définition du *caring* des dimensions non encore explorées par les philosophes. Nous présenterons ici les idées de quelques-unes de ces infirmières, de façon à pouvoir mesurer l'importance de leur contribution.

### *La conception du caring en sciences infirmières*

En sciences infirmières, les premières études sur le *caring* ont été menées par Leininger (1981). Au moyen d'une vaste étude ethnographique, elle a répertorié les diverses formes du *caring* à travers le monde pour en faire ressortir les caractéristiques. De cette étude naquit chez Leininger l'irréductible conviction que non seulement le *caring* constitue le fondement de l'humanité, mais qu'il représente aussi le concept fondateur et unificateur des soins infirmiers. Selon cette auteure, aucune autre profession ne peut affirmer



avoir pour base le *caring* autant que la profession infirmière. Alors que les conceptions dont il était question précédemment situent le *caring* dans une relation interpersonnelle, celle de Leininger ouvre sur des dimensions sociales et culturelles.

Leininger (1981, p. 9) propose trois formes de *caring* qu'elle définit ainsi (traduction des auteures):

Le care / le *caring* : les actes d'assistance, de soutien et d'habilitation posés à l'égard de ou pour un individu ou un groupe qui présentent des besoins d'aide manifestes ou pressentis. Ces actes ont pour but d'améliorer ou de rehausser sa condition ou son mode de vie.

Le *caring* professionnel : ces actions, comportements, techniques, processus et modèles, intellectuellement appris et culturellement acquis, qui permettent d'aider un individu, une famille ou un groupe à maintenir ou à rehausser sa condition de santé ou son mode de vie.

Les soins infirmiers professionnels : ces modes d'assistance humanistes et scientifiques, intellectuellement appris, qui permettent à un individu, à une famille ou à un groupe de recevoir des services personnalisés par le moyen de processus, de techniques et de modes de *caring* spécifiques, culturellement définis ou attribués, afin d'améliorer ou de maintenir des conditions de santé favorables pour la vie ou lors du mourir.

Gaut (1981) recense cinq conditions pour qu'on puisse dire qu'il y a *caring* dans les soins infirmiers : la conscience, les connaissances, le choix des actions, l'intention et le bien-être de l'autre. Elle ajoute que le *caring* est aussi une attitude et une disposition envers quelqu'un, rejoignant ainsi Buber, May et Noddings qui invitent à un engagement affectif et à une implication émotive à l'intérieur de l'expérience.

Pour Watson (1979, 1985, 1988) le *caring* constitue un idéal moral. Sa théorie repose sur des fondements humanistes, scientifiques, phénoménologiques et existentiels et part du postulat que le *caring* ne peut naître qu'au sein d'une relation thérapeutique. Elle propose les dix facteurs suivants comme contributifs au processus de *caring* (traduction des auteures):

1. La formation d'un système de valeurs humanistes et altruistes.
2. L'inspiration de la foi et de l'espoir.
3. Le développement d'une sensibilité vis-à-vis de soi-même et des autres.
4. Le développement d'une relation de confiance et d'aide.
5. La promotion et l'acceptation de l'expression des sentiments positifs et négatifs.

6. L'utilisation créative de la méthode scientifique de résolution de problèmes comme base de la prise de décision.
7. La promotion de l'enseignement et de l'apprentissage transpersonnels.
8. L'organisation d'un milieu physique, mental, socioculturel et spirituel qui procure du soutien et de la protection et qui facilite un changement positif.
9. L'assistance à satisfaire les besoins humains.
10. La reconnaissance des forces existentielles, phénoménologiques et spirituelles.

L'approche du *caring* développée par Benner et Wrubel (1989) a été influencée par la phénoménologie et le féminisme. Ces auteures ont tenté de rendre visible le *caring* en soins infirmiers comme les féministes ont rendu visible et explicite le travail très important, mais caché, des femmes. Selon la perspective phénoménologique qu'elles ont adoptée, le *caring* est la façon d'être la plus fondamentale chez les soignantes. Pour ces auteures, le mot *caring* signifie que les soignantes sont reliées au monde, et que certaines choses, personnes ou idées leur tiennent à coeur et ont de la valeur pour elles. Les auteures ont aussi réfléchi sur la primauté du *caring* comme stratégie d'adaptation au stress et ont démontré cette primauté par les arguments suivants (traduction des auteures) :

1. Parce que le *caring* met en lumière ce qui a de la valeur pour la personne, il met aussi en évidence ce qui sera considéré stressant et indique les modes d'adaptation appropriés.
2. Se préoccuper de quelqu'un ou de quelque chose place la soignante dans une situation telle qu'elle pourra déterminer les stratégies les plus efficaces et les mieux adaptées à la personne qui a besoin d'aide. Et cela non seulement parce qu'elle le sait de manière scientifique, mais parce qu'elle se préoccupe de l'autre par son *caring*.
3. Enfin, le *caring* est primordial pour faire face au stress parce qu'il ouvre sur un éventail de possibilités créatives pour donner de l'aide et pour en recevoir. Une relation basée sur le *caring* favorise la confiance mutuelle et permet à la personne soignée de faire sienne l'aide qui lui est offerte, de se sentir soignée.

En France, Collière (1982) a tracé l'histoire de la pratique soignante des femmes et a introduit la notion de pouvoir libérateur. Elle considère (p. 323) que le pouvoir des soins infirmiers est porteur de «libération» à chaque fois :

1. qu'il permet aux usagers des soins d'utiliser le pouvoir qui leur reste, de mobiliser tout ce dont ils sont capables, y compris leur désir, et de voir avec eux ce qui en permet ou en limite la réalisation;



2. qu'il rend ou accroît le pouvoir d'être, d'autonomie...;
3. qu'il reconnaît le savoir des personnes soignées, qu'il utilise ce savoir et leur permet de l'accroître;
4. qu'il permet aux usagers des soins d'avoir eux-mêmes un pouvoir thérapeutique pour les autres (...).

Au Canada, Roach (1984) s'est également investie dans la description du *caring*. Parmi les principaux éléments de sa réflexion, citons les suivants (traduction des auteures):

1. Le *caring* est une façon d'être humain.
2. Le *caring* n'est pas seulement une émotion ou une attitude. C'est une façon d'être, d'être en relation, d'agir. Il implique une qualité d'investissement et un engagement envers l'autre (une personne, une idée, une chose, ou même soi-même en tant qu'autre) tel que le meilleur de soi s'y exprime. Il est alors possible de toucher à ce qui définit l'être humain le plus intimement et le plus authentiquement.
3. Le *caring* acquiert une dimension professionnelle en soins infirmiers et s'actualise lorsqu'on l'affirme comme une façon d'être humain et lorsqu'on développe la capacité de prendre soin et de se préoccuper des autres, ceci par l'acquisition d'habiletés cognitives, affectives, techniques et administratives nécessaires à l'exercice du rôle d'infirmière ou d'infirmier.
4. Le *caring* se manifeste de façon explicite en soins infirmiers par cinq attributs : la conscience, la compassion, la connaissance, la compétence et l'engagement.

Parse (1981) a défini ainsi le *caring* : «prendre le risque d'être avec quelqu'un en perspective d'un moment de joie» et a explicité chacune des composantes de sa définition de la façon suivante (traduction des auteures):

1. Prendre le risque de : implique pour l'infirmière la possibilité d'avoir mal et de souffrir; implique pour la personne soignée la possibilité d'être rejetée ou bien celle de grandir.
2. Être avec quelqu'un : rejoindre ou se préoccuper de l'autre, ce qui signifie un engagement authentique. Il s'agit d'un effort pour comprendre l'autre en adoptant sa perspective à lui.
3. Moment de joie : joie ultime et immédiate en mouvement complémentaire avec la souffrance. Ici, Parse rejoint Noddings pour qui le sentiment le plus profond que puisse ressentir l'être humain en relation, c'est la joie, et non pas l'angoisse comme l'ont présenté maints philosophes masculins.

Que retenir des conceptions présentées? D'abord, les nuances qu'elles apportent à la description d'une expérience humaine jusqu'ici davantage élaborée par des philosophes masculins. Ces nuances s'enracinent dans l'expérience féminine et professionnelle de prendre soin des autres. Ensuite, chaque conception s'inspire de fondements différents, ce qui permet d'enrichir la compréhension du *caring*. Pour mieux apprécier cette diversité, nous situerons ces conceptions par rapport à leurs fondements.

### *Des conceptions du caring aux modèles*

Il nous est possible de regrouper les conceptions des auteures en sciences infirmières selon quatre modèles. Nous distinguons les modèles ethnographique, humaniste, féministe et phénoménologique (Tableau I).

Tableau I	
Classification des conceptions du caring en sciences infirmières	
MODÈLES	AUTEURES
Ethnographique	Leininger
Humaniste	Gaut
Roach	
Watson	
Féministe	Benner et Wrubel Collière
Phénoménologique	Benner et Wrubel Parse Watson

**Le modèle ethnographique.** Leininger est l'unique représentante de cette façon de concevoir le *caring*. Ce modèle est caractérisé par l'emphase qu'il met sur l'aspect socioculturel du *caring*. Les pratiques de *caring* sont déterminées par la culture et l'environnement social des personnes. Plusieurs autres chercheuses en sciences infirmières se sont inspirées de l'approche de Leininger pour explorer le *caring* dans diverses cultures.

**Le modèle humaniste.** Les conceptions du *caring* qui appartiennent à ce modèle, celle de Gaut, de Roach et de Watson, sont fondées sur une vision de la personne empreinte de valeurs altruistes et humanistes. Ces valeurs constituent des conditions à la manifestation du *caring* et donnent lieu à des attitudes particulières. Selon ce modèle, le *caring* devient un idéal à atteindre et une philosophie de base des soins infirmiers.

**Le modèle féministe.** Développé surtout à la suite des travaux de Gilligan et de Noddings aux États-Unis, ce modèle est centré sur les comportements de *caring* à l'intérieur d'un contexte d'interrelation humaine et basé sur l'expérience et les pratiques de soins des femmes. En sciences infirmières, Benner et Wrubel ainsi que Collière peuvent être associées à ce modèle.

**Le modèle phénoménologique.** La conception du *caring* de Benner et Wrubel est l'exemple le plus éloquent de ce modèle. Selon cette perspective, le *caring* est décrit comme un phénomène empreint de subjectivité et devant être saisi à l'intérieur de l'expérience qu'en a la personne. Watson et Parse situent aussi le *caring* comme un concept phénoménologique.

***Le caring, un phénomène interactionnel, interprétatif et significatif :  
l'apport de l'interactionnisme symbolique***

Alors que les auteures en sciences infirmières ont privilégié jusqu'ici les modèles ethnographique, humaniste, féministe et phénoménologique du *caring*, nous présenterons ici un modèle interactionniste basé sur la théorie de l'interactionnisme symbolique. Nous croyons que ce modèle pourrait jeter une lumière nouvelle sur le phénomène du *caring*. Mais nous retracerons d'abord les origines de cette perspective, ses postulats et ses implications pour une pratique de soins infirmiers centrée sur le *caring*.

Précisons d'abord que, pour nous, le *caring* est une expérience interactionnelle qui évolue dans le temps. Il met en présence une personne, en occurrence l'infirmière qui prend soin des autres, qui s'intéresse à l'expérience de santé et de vie de la personne soignée. Par la communication, les deux personnes explorent ensemble cette expérience et cherchent à lui trouver un sens. Elles choisissent des actions mutuelles significatives, qui sont appropriées à la situation. Comme le *caring* est foncièrement un phénomène de relation et d'interaction, l'interactionnisme symbolique nous semble la meilleure perspective pour le saisir et le comprendre davantage. Cette perspective explique le processus dynamique de l'interaction et de l'interprétation d'une relation en tenant compte des points de vue des acteurs sociaux en cause.

**La théorie de l'interactionnisme symbolique.** L'interactionnisme symbolique est une théorie du comportement humain. En tant qu'approche épistémologique, cette théorie aborde la question «comment peut-on apprendre quelque chose sur l'être humain ou sur les phénomènes qui se rapportent à la vie humaine?» en répondant «en étudiant le comportement humain, particulièrement en replaçant les actions dans leur contexte social». Et à la question ontologique «qu'est-ce que l'être humain?», elle répond «l'être humain est un être d'expérience; il attribue une signification à chacune de ses expériences et agit en fonction de cette signification».

Les fondements philosophiques de l'interactionnisme symbolique remontent au début du siècle et s'enracinent dans le pragmatisme américain, plus particulièrement dans le travail de Mead (1934). De nombreuses recherches en sciences infirmières ont été réalisées à partir de cette théorie (voir surtout Chenitz et Swanson, 1986; et Hardy et Conway, 1988).

Dans la perspective de l'interactionnisme symbolique, l'expérience humaine n'a d'autres sens que celui qui lui est attribué par la personne qui la vit, par un processus de réflexion intelligente. À travers ses expériences, la personne attribue des significations aux phénomènes de son environnement ou de sa vie et agit en fonction de ces significations. Comprendre une autre personne oblige donc à rechercher la signification qu'elle accorde aux phénomènes qui l'entourent. Pour l'infirmière, comprendre la personne soignée nécessite donc de s'arrêter pour comprendre le sens que revêt, pour celle-ci, son expérience de santé ou de maladie. Il est possible d'accéder à la signification qu'attribue une personne à un phénomène en interprétant ses actions. Cette interprétation évolue à travers un autre processus, celui de l'interaction. Mead a postulé que l'interaction peut se produire soit avec d'autres dans un contexte interpersonnel soit avec soi-même dans un contexte intrapersonnel. Une personne peut donc interpréter ses propres actions tout comme elle interprète celles des autres. Mais, dans tous les cas, les actions sont au cœur de la compréhension de l'autre et de soi-même.

Pour Mead (1934), l'être humain est inséparable de son contexte social et culturel. La personne naît dans une société déjà existante. Le contact avec sa famille et d'autres groupes sociaux de son milieu forme la base à partir de laquelle le jeune enfant apprend à reconnaître les phénomènes significatifs de son expérience et à leur accorder une valeur ou un sens particulier. Selon Baldwin (1986), parmi ce que la personne reçoit de la société dans laquelle elle naît, le langage et la parole sont les plus importants, car ils permettent le développement de l'activité mentale, de l'intelligence, du concept de soi, de l'empathie, de la communication et de plusieurs autres formes d'activité sociale. Le langage et la parole constituent une dimension symbolique importante de l'interaction et du *caring*.

Il importe de noter, cependant, que même s'il reconnaît que l'être humain est influencé par son contexte socioculturel, l'interactionnisme symbolique n'adhère pas au principe du déterminisme des actions humaines. Bien que les actions se produisent à l'intérieur d'un contexte donné, la personne détient le pouvoir de construire ses actions en fonction de ses valeurs et de ses buts. Chaque personne apporte à une situation sa propre perspective, ses habitudes, ses interprétations et ses capacités qui interagissent avec les dimensions et les possibilités inhérentes à la situation. Pour Benner et Wrubel (1989), cette interdépendance de l'être humain et de son milieu implique à la fois une «liberté située» et des «possibilités situées».



En tant qu'êtres sociaux, les humains doivent s'entendre entre eux pour vivre en relative harmonie afin d'assurer leur survie, leur croissance et l'actualisation de leur potentiel. Leurs interactions s'harmonisent à travers le processus de communication. C'est par la communication symbolique, par le biais des agirs et des dire, qu'ils expriment réciproquement leurs significations, leurs interprétations et leurs intentions. C'est par «la prise du rôle de l'autre» (Mead, 1934), c'est-à-dire la capacité de se mettre à la place de l'autre, de voir comme l'autre voit, de saisir ce que l'autre ressent et de réagir comme lui, et également par la négociation, que les acteurs sociaux arrivent à s'entendre sur les significations et les interprétations et à articuler leurs actions. Interaction et action (phénomènes observables par les agirs et par les dire) ainsi que signification et interprétation (phénomènes non observables directement sauf par l'interaction et les actions) sont les concepts fondamentaux de la théorie de l'interactionnisme symbolique.

**Le caring comme interaction symbolique.** Le *caring* en soins infirmiers, vu selon la perspective interactionniste, comprend interaction, interprétation et signification. L'infirmière s'engage dans un processus qui devient le lieu d'émergence du sens de l'expérience pour elle et pour la personne soignée. Ce sens se construit au fur et à mesure des interactions entre elle, la personne soignée et toute autre personne significative. C'est ainsi qu'une maladie comme le cancer peut être interprétée dans certains cas comme une expérience de croissance. Dans d'autres cas, cette maladie peut être vécue et interprétée comme une expérience de souffrance intense. Ce que l'infirmière vise, c'est un partage des significations et des buts, ainsi qu'une complémentarité des actions.

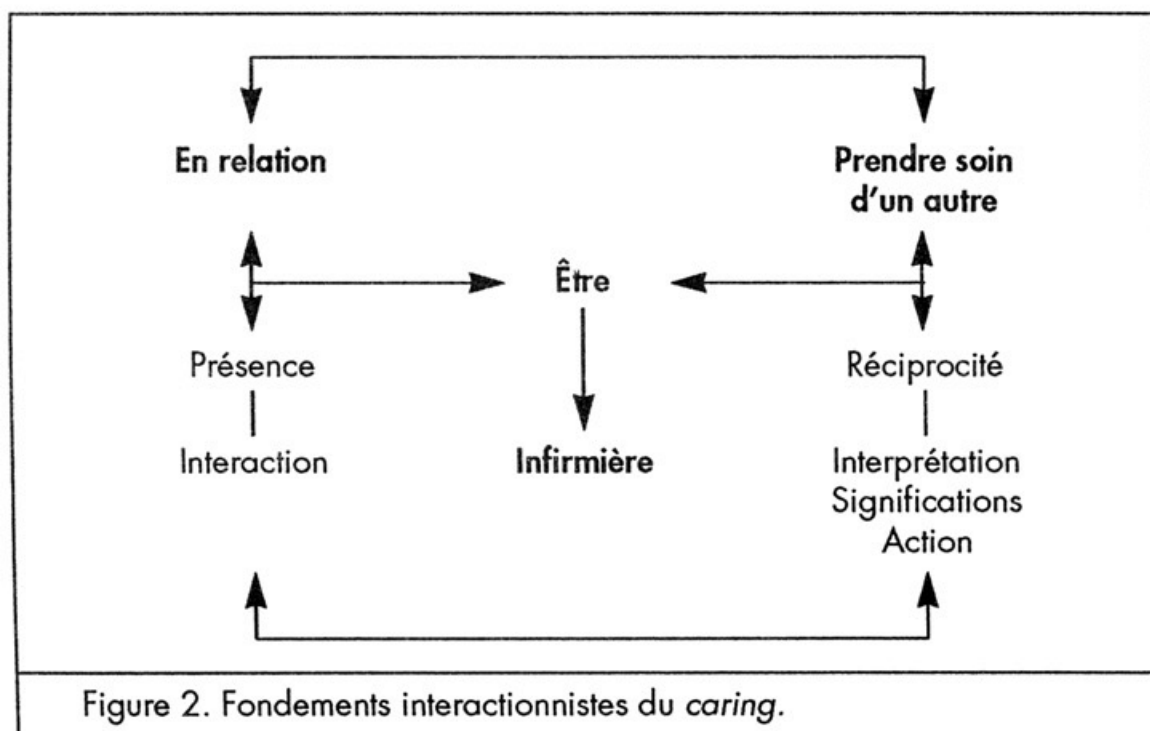
En cherchant à comprendre le phénomène du *caring*, il importe de se rappeler que l'infirmière et la personne soignée proviennent souvent de milieux sociaux différents, même s'ils semblent parfois similaires. Le sens que chaque individu donne à un phénomène est donc à découvrir à chaque fois. Heureusement, l'expérience humaine comporte des dimensions universelles, et l'habileté à communiquer facilite la mise en commun de significations associées aux diverses expériences. L'infirmière et la personne soignée peuvent donc arriver à se comprendre même dans des situations critiques de santé et de vie.

Quoique le *caring* soit une capacité humaine universelle, sa manifestation varie selon les caractéristiques particulières de chaque individu. La capacité d'agir en tant que soignante ou en tant que soignée diffère donc d'une personne à l'autre. Certaines sont plus à l'aise dans le rôle de soignante, d'autres dans le rôle de soignée. Et certaines choisissent de s'engager dans une profession centrée sur le *caring*.

Qu'attendons-nous d'une personne qui exerce une profession axée sur le *caring*, en l'occurrence celle d'infirmière? Être infirmière exige la compréhension de l'expérience de l'autre. Pour Mead, cela implique prendre le rôle de l'autre, se mettre «dans les souliers de l'autre». Notre conception de ce qu'il faut faire pour comprendre l'autre diffère de celle de Mead, pour se rapprocher davantage de la conception du *caring* mise de l'avant par les philosophes dont il était question précédemment. Pour nous, il ne s'agit pas de se projeter dans l'autre, ni de prendre sa place, ni son rôle, mais plutôt de recevoir l'autre en soi, de «prendre en soi» l'autre et son expérience, afin de «prendre soin» de lui.

Le *caring* implique une relation de réciprocité. A l'intérieur d'une relation le moins prolongée, les rôles de soignante et de soignée peuvent s'inverser à certains moments, tant dans une relation professionnelle que dans une relation personnelle. Dans un tel cas, comment l'infirmière envisage-t-elle la réciprocité? Accepte-t-elle de s'ouvrir à la personne qu'elle soigne pour partager ses propres significations, valeurs, et connaissances, le sens qu'elle donne à son travail, l'importance qu'elle accorde à la santé, à la vie, à sa relation avec la personne soignée? Accepte-t-elle d'être écoutée par celle-ci, d'être confrontée par elle, de négocier avec elle dans une relation réellement de *caring*?

Ayant présenté le *caring* selon la théorie de l'interactionnisme symbolique, il nous est maintenant possible d'intégrer à la Figure 1 les concepts propres à cette perspective. C'est ainsi que dans la Figure 2, l'infirmière est en relation et en interaction. Prendre soin d'un autre implique une interprétation des agirs et des dires de la personne soignée, un partage de significations et une action complémentaire.



Il n'y a pas que dans la dyade soignante-soignée que le *caring* puisse se manifester. L'infirmière est à l'affût des manifestations de *caring* chez la personne soignée et ceux qui l'entourent (famille, amis, collègues, autres proches). Elle facilite la communication entre ces personnes, ainsi que le partage des significations. Elle favorise aussi les actions de *caring* posées à l'égard de la personne soignée par ses proches et elle permet également à la personne soignée d'exprimer du *caring* envers ceux-ci, selon ses capacités et selon la situation.

### Vers de nouveaux savoirs

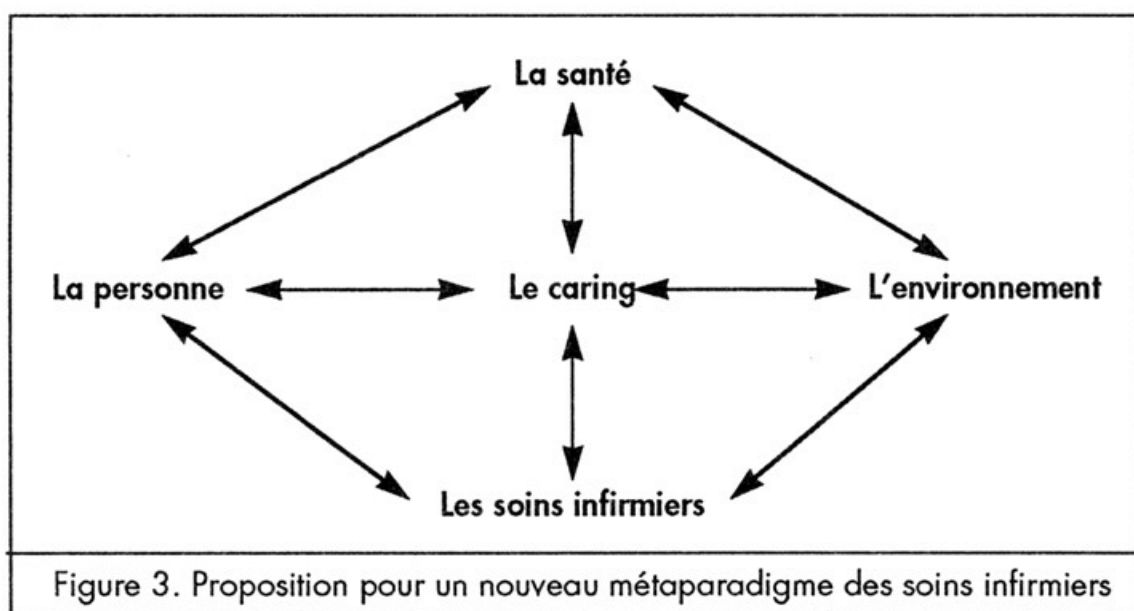
En tant que phénomène humain, le *caring* a donné lieu à de nombreuses définitions. Nous en avons présenté quelques-unes et nous avons abordé leurs fondements philosophiques. Nous n'avons, bien sûr, fait qu'un survol de ce concept, mais l'éventail proposé nous paraît suffisant pour rendre compte de la diversité des conceptions du *caring* et de leurs convergences.

Nous avons ensuite présenté notre conception du *caring* comme «expérience interactionnelle», conception basée sur la théorie de l'interactionnisme symbolique. L'intérêt de cette théorie est qu'elle permet de décrire et d'expliquer le processus relationnel du *caring*. L'interactionnisme symbolique permet aussi d'insérer le *caring* dans sa dimension sociale. Notre conception exprime l'importance de l'interaction, de la signification, de l'interprétation et de l'action pour comprendre ce phénomène essentiellement humain, qui est au cœur des soins infirmiers.

Les soins infirmiers ont pris naissance et évolué à partir du besoin de *caring* exprimé par la société. Au cœur de la pratique des infirmières se trouve le besoin de *caring* et la volonté ou le désir de répondre à ce besoin. Depuis plusieurs années, les analystes des écrits portant sur les modèles conceptuels ou les théories des soins infirmiers semblent d'accord pour affirmer qu'il existe un métaparadigme en sciences infirmières composé de quatre concepts fondamentaux : la personne, l'environnement, la santé et les soins infirmiers. Nous proposons d'ajouter à ce métaparadigme un cinquième concept, celui de *caring* (Figure 3). Le *caring* réciproque est vraiment au centre des relations entre la personne, son entourage, sa santé et l'infirmière. De façon ultime, les soins infirmiers visent à ce que s'établisse un *caring* mutuel entre la personne et son entourage sans que le soutien professionnel soit nécessaire.

Ce métaparadigme des soins infirmiers ayant comme concept central le *caring* permet de rompre avec la perspective positiviste qui domine les sciences depuis plus d'un siècle. Cette perspective, qui opère un clivage entre l'esprit et la matière, entre le corps et la psyché, et qui valorise l'objectivité et

la recherche d'une seule vérité, a été fortement critiquée en sciences humaines et même en sciences physiques. Le métaparadigme que nous proposons, inspirée par l'interactionnisme symbolique, relève de la perspective constructiviste selon laquelle les acteurs sociaux construisent des visions multiples et holistiques du monde et de la réalité. Malgré ces différences, des consensus sont possibles, ce qui permet de produire les actions cohérentes. En accordant une place privilégiée au *caring* en soins infirmiers, l'on affirme la préséance de la relation et de l'interaction, de la parole en tant que symbolique, et de la nécessité du partage de significations et d'un effort interprétatif pour faire sens de l'expérience de soins. L'on affirme aussi que ce partage de sens permet de produire des actions de *caring*. Nos espoirs reposent sur ce métaparadigme pour l'avancement des connaissances en sciences infirmières.



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# **Nursing Education Content in Master's in Nursing Programs**

**Joan S. Ford and Dana Hames Wertenberger**

L'admission à la pratique infirmière au niveau du baccalauréat présume qu'il y a des infirmières adéquatement préparées pour enseigner à ce niveau. Cette étude a pour but de décrire le contenu relatif à la préparation des enseignantes dans les programmes de maîtrise en sciences infirmières au Canada. Cette étude est une répétition partielle de l'étude d'Oermann et Jamison (1989) qui portait sur les programmes américains de maîtrise en sciences infirmières. Un questionnaire et une lettre explicative furent postés aux doyens/directrices des dix programmes de maîtrise canadiens de langue anglaise. Le pourcentage de retour des questionnaires fut de 100%. Sept des dix programmes offrent un ou des cours concernant l'éducation tandis que pour deux des trois autres, il est requis de suivre un ou des cours en éducation offerts par d'autres facultés. Les résultats indiquent que les cours relatifs à l'éducation en sciences infirmières incluent une variété de sujets. Aucun modèle ne se dégage de cette étude quant aux exigences pour la préparation au rôle d'infirmière enseignante. Des questions sont donc posées à savoir si au Canada anglais les programmes de maîtrise en sciences infirmières offrent en ce domaine une préparation adéquate.

Baccalaureate entry into practice presumes that there is a cadre of nurses with adequate preparation to teach students at the baccalaureate level. The purpose of this study was to describe the nursing education component of Canadian master's in nursing programs. This study was a partial replication of Oermann and Jamison's (1989) study of master's in nursing programs in the United States. A questionnaire and cover letter were mailed to the Deans/Directors of the 10 Canadian master's programs where English is the language of instruction. The return rate was 100%. Seven of the 10 programs offered nursing education coursework, while two of the remaining three required education coursework outside of nursing. The findings indicate that the nursing education courses covered a variety of topics, but had no fixed requirements for preparation for the role of nurse teacher. We question whether current master's in nursing programs constitute adequate preparation for the role of nurse teacher in English Canada.

The Canadian Nurses Association (CNA) and various professional associations are in favour of having the baccalaureate degree as the minimal educational qualification for entry into nursing practice by the year 2000. This position requires an adequate number of qualified nurse educators, yet there has been no systematic attempt to determine if Canadian master's in nursing programs are preparing students for the role of nurse teacher. The current study attempts to address this issue by focusing on the nursing education component in master's in nursing programs in Canada.

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### Literature Review

Very few reports have been published on master's education as preparation for the role as nurse teacher. A 20-year review of the literature indicated that the teacher role has been identified as appropriate for master's prepared nurses (McPhail, 1971). Moreover, a study of nurses who had undertaken master's degrees in a clinical area indicated that they preferred a program that also included teaching, administration and clinical preparation. (Donley, Jepson, & Perloff, 1973).

Fitzpatrick and Heller (1980) identified a dearth of qualified nurse educators. They expressed concern about the proliferation of clinically focused master's programs, with a concomitant decrease in teaching and administration oriented programs. This shift toward preparation for advanced clinical practice at the master's level had decreased the pool of nurses who were prepared for the role of nurse educators. These authors identified several problems that arose when clinicians were used to fill teaching roles, including: lack of understanding of the teaching function, curriculum development, test design and evaluation; and poor socialization into the academic milieu. Substantial institutional resources were therefore diverted into educating new faculty members to fill the roles for which they were hired. Moreover, Beare et al. (1980) identified actual and ideal content in master's curricula, and found that of 53 content areas only three were related to the teaching role (teaching-learning process, teaching-learning theory, and testing and measurement). In addition, less than 25% of the programs in their study offered any content related to the teaching role.

McKevitt (1986) compared National League for Nursing-accredited master's programs for 1979 and 1984 to identify trends in master's of education in nursing over a five-year period. The 1979 sample consisted of 81 master's level graduate programs, and the 1984 sample consisted of 118 programs. The data came from program catalogues and brochures, and the 1979 and 1985 editions of *Master's Education in Nursing: Route to Opportunities in Contemporary Nursing*, published by the National League for Nursing (NLN). The data were analyzed, "to identify changes in program admission requirements, program offerings, and thesis or comprehensive examination requirements" (McKevitt, 1986, p. 225). McKevitt found a significant decrease in the number of nursing programs offering education as a primary area of study between 1979 and 1984. This is associated with an increase in specialty major areas of clinical practice and gives credence to Fitzpatrick and Heller's (1980) concerns.



To examine the nursing education component of master's programs in the United States, Oermann and Jamison (1989) conducted an exploratory descriptive study using a mailed questionnaire. The questionnaire consisted of 26 open- and closed-ended questions. There were three sections to the questionnaire addressing: (a) characteristics of the master's program in nursing; (b) characteristics of the nursing education functional areas; and (c) characteristics of the respondent. For sample questions from each of these sections see Figure 1, next page.

Of 139 possible respondents (all NLN accredited master's programs), 92 (66.2%) completed the questionnaire. Of these, 10 (10.9%) programs offered a major in nursing education; 66 (71.7%) programs offered some coursework in nursing education; and 15 (16.3%) programs offered no courses in nursing education. A literature review revealed that no comparable study had been conducted of master's nursing programs in Canada. However, Stinson, Field and Thibaudeau's (1988) overview of "selected characteristics of Canada's 11 nursing masters' programs" 1985-1986 (p. 344) revealed that only three programs offered a nursing education option. Therefore, the purpose of this study was to identify and describe the nursing education component in Canadian master's in nursing programs.

### **Method**

This was an exploratory descriptive study using a mailed questionnaire. The study proposal was approved by the Faculty of Nursing Ethics Committee. The inquiry was, in part, a replication of a study conducted by Oermann and Jamison (1989) in the United States. We obtained permission to use and/or adapt the questionnaire from the senior author.

The questionnaire was mailed to the Deans/Directors of the 10 master's in nursing programs (where English is the language of instruction) in Canada. A cover letter invited participation in the study, explained its purpose, and gave instructions for completing and returning the questionnaire. Three weeks later, a follow-up postcard reminder was sent to each of the Deans/Directors. Consent to participate was implied by return of the completed questionnaire.

The self-administered questionnaire was designed to collect information about: (a) the characteristics of the master's in nursing program and (b) the nursing education component of the program. Oermann and Jamison (1989) stated that content validity and reliability of the researcher-developed questionnaire were established in a pilot project, but no details are available. In order to adapt the instrument for use with a Canadian population we deleted questions which were not relevant, such as "Is your Master's Program accredited by the National League for Nursing?" and substituted "courses" for "credit hours." A panel of expert nurse educators reviewed the revised instru-

**Figure 1****Sample questions from Oermann and Jamison's (1989) data collection tool.**

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**I. Characteristics of Master's Program**

3. What types of Master's Programs are available to students?

- \_\_\_\_\_ 1. Full-time.
- \_\_\_\_\_ 2. Part-time.
- \_\_\_\_\_ 3. Full-time and Part-time.

6. What degree is awarded upon completion of your Master's Program?

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8. What are the purposes of your Master's Program?

(Check all that apply)

- \_\_\_\_\_ 1. Prepare clinical nurse specialists.
- \_\_\_\_\_ 2. Prepare nurse administrators.
- \_\_\_\_\_ 3. Prepare nurse educators.
- \_\_\_\_\_ 4. Other.

**II. Characteristics of Nursing Education Functional Area**

10. What types of programs do you offer in nursing education?

- \_\_\_\_\_ 1. Major in Master's Program.
- \_\_\_\_\_ 2. Minor in Master's Program.
- \_\_\_\_\_ 3. Other:

12. What is the number of *required* nursing courses? \_\_\_\_\_

13. What is the number of elective nursing education courses? \_\_\_\_\_

14. Do students complete education courses other than ones in nursing education?

- \_\_\_\_\_ 1. Yes.
- \_\_\_\_\_ 2. No.

**III. Characteristics of Respondent**

23. What is your current position? \_\_\_\_\_

25. What is your highest degree?

- \_\_\_\_\_ 1. Doctorate in nursing.
- \_\_\_\_\_ 2. Doctorate in other field.
- \_\_\_\_\_ 3. Master's in nursing.
- \_\_\_\_\_ 4. Master's in other field.
- \_\_\_\_\_ 5. Other (specify)

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Note: The senior author provided us with the questionnaire.

ment for validity. Several suggested changes were incorporated into the final version. Although Oermann and Jamison (1989) analyzed their data using descriptive statistics, t-test and chi square, such analysis was not possible in the current study due to the small sample size. Instead, data were analyzed using descriptive statistics.

## Results

### *Characteristics of the Master's Programs*

The 10 master's programs surveyed offered opportunities for full- or part-time study. Admission requirements included: (a) a baccalaureate degree in nursing (although three programs also admitted registered nurses with non-nursing baccalaureate degrees); (b) the minimum equivalent of a B average (one program also required a Graduate Record Examination total score of 1500); (c) all but one program required an undergraduate statistics course; (d) six programs required one or more years of clinical nursing experience; and (e) six programs required a research methods course. In addition, five programs required evidence of current nursing registration or eligibility for registration.

According to our findings, each year approximately 217 to 231 students enrol in master's programs and 160 to 179 students graduate. These figures are not in agreement with the data available in *A Compendium of Canadian Graduate Programs in Nursing 1991* (CAUSN, 1991). The latter reports approximately 171 to 202 admissions ( $n=9$ , one school did not respond), and approximately 141 graduates in 1990 ( $n=9$ , another school did not respond).

In the current study, the number of full-time faculty who taught exclusively in the graduate programs ranged from 1 to 11, with a mode of 6. In one program, the faculty taught in both the undergraduate and graduate programs. For faculty who taught part-time in the graduate program, the range was 2 to 10 with a mode of 5.

Of the nine respondents who answered the question regarding the purpose(s) of the program, all prepared graduates for more than one role: eight prepared advanced level nurse clinicians, eight prepared nurse administrators, seven prepared nurse educators, and four nurse specialists/nurse practitioners. The number of courses/credits required to complete the degree varied from institution to institution. At the end of the master's program, six programs awarded an MN degree, three an MScN degree, and one either an MSc or an MSc (applied).

### *Characteristics of the Nursing Education Courses*

The findings revealed that seven of the 10 master's programs offered nursing education coursework; of the other three, two required students to take education courses from another discipline.

The number of nursing education courses offered in six of the seven programs (the respondent from one program did not complete the page with this information) were as follows: two programs offered one nursing education course, three programs offered two courses, and one program offered a full course plus six half courses. In two of the six programs nursing education courses were required, and in two other programs they were elective. Five of the six programs offered at least one elective, but in one case the elective was offered in alternate years.

Typically, respondents indicated that the purpose of the nursing education coursework was to prepare the graduates for teaching in a college/university setting (e.g., diploma/baccalaureate nursing programs). Graduates from one program were also prepared to teach in a clinical setting such as staff development, or patient/health education. Each year a total of approximately 47 to 55 students chose nursing education coursework and between 41 and 48 of the graduating class completed nursing education coursework.

In four programs the required courses in nursing education included content on learning theory, curriculum development theory, teaching methods, testing, grading/marking, evaluation theory, clinical teaching and evaluation, teacher evaluation, and academic advisement and counselling (Table 1). Only one program included content on multimedia and computer-assisted instruction. Four programs offered electives in nursing education. The electives included course content in curriculum development theory, teaching methods, evaluation theory, clinical teaching, program evaluation, and accreditation. Only one program offered a practicum elective.

The nursing education courses provided students with a variety of learning experiences. The most frequently reported experiences were: curriculum/course development, classroom and clinical teaching, academic advisement and counselling, test construction, development and use of media, grading/marking student assignments, clinical evaluation of students, evaluation of classroom teaching, and program evaluation (Table 2). In two programs, students who chose nursing education coursework were required to take an elective(s) in education.

The number of faculty teaching the nursing education courses in each program ranged from 1 to 3, with a mode of 1. The highest academic degree held by these faculty members were as follows: doctorate in nursing, two;



doctorate in other than nursing, four; master's in nursing, two; master's in other than nursing, two.

### Discussion

All the master's programs provide opportunities for full- or part-time study, allowing nurses who are employed to pursue graduate education as part-time students. Emphasis of the master's programs is primarily on the preparation of advanced level practitioners. Hence, the programs provide opportunities for students to develop knowledge and clinical expertise. One positive result of this focus is that it ensures aspiring nurse educators are

**Table 1**

**Frequencies of Course Content/Topics in Required and Elective Courses, as Reported by Respondents (N=7)**

<sup>1</sup> Content	Required n	Electives n
No required nursing education courses	1	
No elective nursing education courses		2
Learning theory	4	
Curriculum development theory	4	3†
Teaching methods	5	2†
Instructional design	2	1†
Multimedia	1	—
Computer-assisted instruction	1	—
Testing	4*	1†
Grading/marking	4	—
Evaluation theory	5	2†
Clinical teaching	5	2†
Clinical evaluation	5	1†
Program evaluation	3	2†
Accreditation	2	2†
Teacher evaluation	5*	1
Academic advisement and counselling	4*	—
a) Other: Brief discussion of student/teacher rights; and philosophy of education	1	—
b) Other: Historical examination		1

\* One of the respondents reported limited coverage of these content areas.

† For one program the elective is a practicum.

1 Source: M.H. Oermann and M.T. Jamison, *Nursing Education Component in Master's Program* questionnaire. Unpublished.

**Table 2**

**Frequencies of Types of Learning Experiences in Master's Programs, as Reported by Respondents (N=7)**

<sup>2</sup> Learning Experiences	n
Classroom teaching experience	3
Clinical teaching experience	4
Academic advisement and counselling	3
Clinical evaluation of students	4
Curriculum/course development	6
Test construction	4
Grading/marking of students	3
Development of media	3
Use of media	3
Evaluation of classroom teaching	3
Program evaluation	5
Other (please specify):	
Post conference teaching; and either lab teaching or seminar/lecture	1

1 Source: M.H. Oermann and M.T. Jamison, *Nursing Education Component in Master's Program* questionnaire. Unpublished.

competent practitioners. Practitioner competence for teachers was identified as "the single most important finding" of McLane's study (1978, p.53).

Seven of the 10 master's programs offer some coursework in nursing education. Furthermore, these programs all claim that one of their purposes is to prepare nurse educators. In other words, students who enrol in any one of these programs can pursue a program of study to prepare them to be teachers of nursing. Our conjecture is that the nursing education component provides only an overview of curriculum design, test construction, clinical teaching and evaluation methods, instruction strategies, and technology. These have been identified as "basic competencies" for nurse educators (Fitzpatrick and Heller, 1980). Graduates of these programs may therefore not acquire the in-depth knowledge and skills that are considered foundational to the teaching role. In addition, although significant gains are being made in the availability of computer aided instruction programs, multimedia teaching aids, and interactive videos, only one program provides any opportunity for learning about these.

In order to achieve in-depth knowledge in the relevant areas, more extensive nursing education coursework would be required. However, this does not

mean that all of the courses must be taught by nursing; some, such as test construction, instruction strategies, and technology, could be taken as electives in other disciplines. Courses in curriculum design, clinical teaching, and evaluation methods should be taught by nurses, as the content for these courses must be relevant to the perspectives and goals of nursing.

In conclusion, we found that seven out of 10 Canadian master's in nursing programs offer nursing education coursework. But, inasmuch as each course covers a variety of topics, and the number of nursing education courses in any program is very limited, it may be that Canadian master's in nursing programs are not adequately preparing students for the role of nurse teacher. To pursue this issue from a different perspective, we are planning a future study to explore what nurse educators have to say about their educational preparation for teaching.

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# Emotions Experienced and Coping Strategies Used by Family Members of Organ Donors

Maryse Pelletier

*Lazarus et Folkman (1984) examinent dans cette recherche descriptive Stress and coping theory (théorie du stress et les façons d'y faire face) les réactions émotionnelles et les stratégies pour y faire face employées pendant les périodes d'attente et de conflit au moment du don d'organes. Sept familles de l'est du Canada qui avaient perdu un être cher de façon brutale et qui avaient consenti à un don d'organes ont été interviewées chez elles. Les conclusions ont clairement montré que les membres de la famille ressentaient des émotions diverses et employaient différents types de stratégies pour y faire face. Les conclusions de cette recherche permettent d'approfondir la connaissance nécessaire pour guider les interventions en soins infirmiers afin d'offrir des soins délicats aux membres de la famille de donneurs d'organes.*

In this descriptive study guided by the Lazarus and Folkman (1984) stress and coping theory, donor family members' emotional responses and coping strategies used during the anticipation and confrontation stages of the organ donation experience were explored. Seven families from Eastern Canada who had lost a loved one suddenly and consented to organ donation were interviewed in their homes. The findings clearly showed that family members experienced a variety of emotions and used several different types of coping strategies. The findings of this study contribute to the development of knowledge required to guide nursing interventions to provide sensitive care to family members of organ donors.

A life-threatening illness is a highly stressful event. Most family members of organ donors would agree that the degree of stress experienced is magnified when a loved one dies after a brief illness (Pelletier, 1992). Family members are usually shocked, as they have had little time to prepare themselves emotionally for the tragedy (Pittman, 1985). The acute and profound grief can interfere with their ability to absorb and comprehend information, to problem solve, to make decisions, and to use effective coping skills (Fulton, Fulton, & Simmons, 1977; Elliot & Smith, 1985). However, it is often under these circumstances that they must make the decision whether or not to donate their loved one's organs and/or tissue. There is a paucity of research available to guide nurses in developing supportive interventions to help family members of organ donors cope. Therefore, this paper describes the type of emotions experienced and coping strategies used by these individuals during the anticipation and confrontation stages of organ donation.

The framework used for this study was based on the cognitive-phenomenological theory of stress and coping by Lazarus and Folkman (1984). It

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emphasizes a complex and dynamic process between appraisal of a stressful event, emotional responses, and coping. The theory also proposes that although several individuals may experience the same event, their appraisal of the significance of the event, manifestations of emotions, and use of coping strategies will differ.

Coping refers to efforts initiated by an individual to master, change, or tolerate the demands of a situation "that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 41). These coping strategies are employed to solve the problems causing the distress (problem-focused coping) and regulate emotions (emotion-focused coping). Problem-focused coping involves efforts directed at problem solving, decision making, weighing costs and benefits, and choosing and acting. These coping strategies are more likely to be used when the circumstances of a situation can be altered and the potential for control exists. In contrast, emotion-focused forms of coping involve efforts to lessen emotional distress and are more likely to be used if an event is appraised as unalterable (Folkman & Lazarus, 1988). Although both forms of coping have specific functions, they are often used simultaneously for greater effect. According to Folkman and Lazarus (1988), emotion both facilitates and interferes with coping, and coping either increases or decreases distress.

### Literature Review

Few studies have examined responses of family members to the organ donation experience. None of the four studies (Bartucci, 1987; Morton & Leonard, 1979; Fulton, Fulton, & Simmons, 1977; Savaria, Rovelli, & Schweizer, 1990) and two reports (Christopherson & Lunde, 1971; Lange, 1992) that were conducted had a theoretical base. Collectively, these investigators identified: (a) the factors which motivated families to donate; (b) the role of organ donation in helping families cope with grief; and (c) the stress associated with the diagnosis of brain death and deciding to donate. Factors which motivated the family's decision to donate centered on the desire to respect the donors' wish to donate, help others, and create a positive outcome. Most family members reported that organ donation helped make the tragedy a more positive experience. Knowing that someone was living a normal life, and that part of their loved one lived on lessened the pain of having lost their loved one. In contrast, others reported negative feelings about organ donation that were related to: the manner in which they were approached; the removal of organs other than those consented to by the family; the donor's face not being recognizable due to the removal of eyes; the organ's being used for reasons other than transplantation; and the difficulty of keeping their loved one on life support and subjecting them to surgery. Several sources of stress that were reported by family members in relation to the diagnosis of brain

death and making the decision to donate included: (a) receiving insufficient information about the meaning of brain death; (b) parting with the loved one when the donor did not seem fully dead; (c) waiting for the organs to be retrieved; and (d) not being told when the removal of organs was completed. None addressed the type of coping strategies used by family members of organ donors. As reported by Lazarus & Folkman (1984), coping is situation-specific and must be evaluated in relation to the context in which an event occurs.

### **Method**

A retrospective, exploratory, descriptive study was undertaken to identify the family members' appraisal of the most stressful situations, emotions experienced, and coping strategies used during the organ donation experience. We have already reported elsewhere on the first of these three factors (Pelletier, 1992).

### ***Sample***

A total of nine individuals from seven families who had consented to organ and/or tissue donation in 1988 participated in the study. Their relationships to the donors included: three mothers, two fathers, one husband, two wives, and one sister. The donors had been involved in motor vehicle accidents resulting in head injuries or other tragedies in which death was sudden and unexpected. Their ages ranged from 16 to 41 years. All families consented to organ donation within 1 hour to 3 weeks of the donors' admission to a critical care area. Interviews were held at 10 to 15 months after death of the loved one.

### ***Data collection***

Family members of organ donors were initially contacted by a letter from the Transplant Coordinator. Upon receipt of a response letter, the investigator telephoned the family members to explain the study. Once verbal consent was obtained, an interview was arranged. Written consent was obtained and confidentiality of all information was assured. The family members participated in a tape-recorded semi-structured interview of 1- to 4-hour duration in their homes. The interview guide consisted of 18 open-ended questions. Seven of these questions were designed to identify the coping efforts used by family members to manage the most stressful situations during the anticipation and confrontation stages of organ donation. During the anticipation stage, for example, when a family member reported the uncertainty of the outcome as most stressful, a coping strategy question was then asked: "What did they do that helped them to manage uncertainty about whether the loved one would survive or die?" If a family member had difficulty understanding the word "manage", terms such as "handle", or "deal with" were substituted.

*Data Analysis*

The taped portions of the interviews were transcribed verbatim and the information categorized using content analysis. The steps used to analyze the data followed Wilson’s (1985) format, which included: (a) deciding upon and defining the unit of analysis, (b) developing a set of categories, (c) developing the definitions of categories and the rules to guide the coding of units into categories, and (d) coding the units into categories. Each transcript was reviewed in its entirety for major themes. The system for categorizing emotions and coping strategies was based on the family member’s perception, previous research of families of critically ill patients and organ donors, and the conceptual framework. A single unit of analysis consisted of sentences, phrases, or passages that described a single emotional response or coping strategy. All categories were designed to be mutually exclusive and collectively exhaustive (Table 1).

The instrument was pilot tested and reviewed to establish content validity by three nurses researchers, one of whom was an expert in Lazarus and Folkman’s (1984) theory and content analysis. Reliability was ensured by having the investigator conduct all of the interviews, and the thesis advisor verified two transcripts to ensure that the interviewer remained objective. Inter-rater reliability was determined by the investigator and an independent rater experienced in this type of analysis. Raters coded two randomly selected tran-

Table 1. Emotions and Coping Strategies of Family Members of Organ Donors		
	Anticipation Phase	Confrontation Phase
Most Stressful Situation	Threat to Life(9*)	Diagnosis of Brain Death(9)
Emotions Experienced	Helplessness(3) Sadness(2) Numbness(2) Panic(1)	Disbelief(5) Shock(3) Numbness(1) Anger(1) Sadness(1)
Coping Strategies Used	Seeking Information(9) Seeking Emotional Support(9) Keeping the Connection(9) Escape-Avoidance(8) Planful Problem-Solving(6) Exercising Control(5)	Consenting to Organ Donation(9)
*The numbers in parentheses are the number of individuals who described an experience fitting that category (maximum = 9)		



scripts using Cohen's Kappa (k) to measure reliability for each category. The reliabilities for the emotional responses were  $k = 1.0$ , and for the coping strategies k ranged from 0.78 for escape-avoidance to 1.0 for making the suggestion to donate. According to Fleiss (1981), this range of values for kappa represents good to excellent agreement beyond chance.

## Results

### *Anticipation Stage*

All family members appraised the acute phase and the threat of losing the loved one as being the most stressful time. Unresponsiveness and deteriorating health provided tangible evidence that the loved one's life was at stake, but this unstable condition made family members uncertain about whether the loved one would survive or die. In response they reported experiencing a variety of emotions and using a combination of six types of coping strategies (Table 1).

**Seeking Information.** All family members reported needing information about the loved one's condition, progress, and prognosis. They sought information by: (a) questioning health professionals to obtain and clarify information; (b) remaining near and visiting frequently to observe changes in the loved one's condition; and/or (c) using a problem-solving approach to draw on past experiences with life-threatening illness, hospitalization or death to interpret the present or predict future implications of their own situation. Such information seemed to either increase or decrease their emotional distress. It reduced their distress by helping them to evaluate what was happening and prepare "to take whatever was to happen." Conversely, as family members became aware of the seriousness of the illness/tragedy, their realization that nothing could be done to alter the outcome generated feelings of helplessness. One spouse poignantly described "not being able to make him [her husband] hang on [or] ... do anything to make him feel better.... I should have been able to give him my strength by just touching him, he should have been cured." Two other family members reported feeling "sad" in response to seeing their loved one acutely ill and surrounded by equipment and tubes. One father said, "I couldn't stay very long because it was too hard." Two other family members described being "numb" during this critical and uncertain period. One spouses reported that she "wasn't really in touch with reality. I couldn't think, feel, or hear.... My mind was dull." Only one family member experienced a feeling of panic, "when three days passed, he still had not woken up.... I thought, 'I've got to wake him up.'"

**Seeking Emotional Support.** Family members sought support, comfort, sympathy, and expressions of understanding from family and friends in the form of visits or phone calls at the hospital or home. One spouse seemed to

speak for all family members when he commented that, "The contact with people from the church, friends, and relatives was the most important and helpful thing... I was just overwhelmed by the amount of support." Family members also reported being comforted by some members of the health care team; nurses were singled out as being the most helpful health professionals in providing information and emotional support. They were described as being "kind," "concerned," "fantastic," and "sympathetic" (Pelletier, 1992). One mother remembered: "...one particular nurse. She was so kind. I broke down, she stayed with me. I remember her kindness, how sympathetic she was, that meant a lot to me."

**Exercising Control.** Five family members reported that exercising control over their emotions helped them to conceal from others how they were feeling. For one mother, it was particularly important that her children not see her cry because, "I didn't want to upset them. I didn't want them to think I was scared."

**Escape-Avoidance.** Eight family members reported diverting their thoughts from the situation by using escape-avoidance strategies. Some deliberately distracted themselves from thinking about the painful reality of the situation by relying on the dulling and numbing effects of alcohol and psychotropic medication. For others, waiting for the outcome became more tolerable when they engaged in activities such as work or exercise. Two members of the same family engaged in wishful thinking and hoped for an improved outcome despite the fact that "the doctor said he 'could live an hour, two days or two weeks,' and if by chance a miracle happened, if he did live, he would be nothing but a 'vegetable.'" Two individuals refused to believe that the illness/tragedy was life-threatening. One spouse believed that everything would be all right once her husband had rested as "he was so tired.... I just wanted his head and his body to heal."

### **Confrontation Stage**

When family members were confronted with the diagnosis of brain death, all reported being unprepared to accept the news. They concurred that the presence of life signs and/or the absence of visible signs of injury made the diagnosis stressful and difficult to comprehend. One spouse explained that she "could have accepted it [the diagnosis] a lot easier, if only I could have seen that he [the husband] was dying. He had no physical injuries, he appeared alive. His heart was pumping... How could I believe that he was dead?" For one mother the pronouncement of death in the absence of certain neurological signs seemed to contradict the traditional definition: "When you die you stop breathing."

All family members showed overwhelming feelings of disbelief, shock, numbness, anger and/or sadness when the diagnosis of brain death was confirmed. Five family members reported a feeling of total disbelief. One mother said, "It was hard to believe that this was happening. One minute you talk to someone, and the next minute they're gone." For a sibling, disbelief was combined with anger directed at the physician: "I was angry. I remember asking the doctor, 'What do you mean, he's brain dead? You told us that G. was a very sick boy; now you tell us that he's brain dead.'" Three family members were shocked at the announcement. For one mother, this feeling was accompanied by a sense of having been overpowered: "It was like I had been – I don't know – hit ... the breath knocked out of me." One spouse remembered feeling extremely "sad" as he "realized that this would be the last time I'd ever touch her [his wife] as a soft, warm, living, [and] breathing human being." Only one coping strategy was used during the confrontation stage: family members made the suggestion of organ donation.

***Making the Suggestion to Organ Donation.*** Despite being in a state of shock and disbelief, all family members courageously consented to organ donation. Five of the seven families took the initiative; for the other two families the issue of organ donation was raised by the physician. In fact, one did not remember their loved one's wishes until approached by the physician. Then they remembered: "what G. [their son] wanted... If he [the physician] hadn't asked, I wouldn't have thought of it myself." Organ donation had been a subject of previous family discussion in six of the seven families and recollection of such conversation facilitated their decision to consent. One mother explained that "[consenting to organ donation] was very important, because this is something P. felt quite strongly about... He had talked about this many times over the years." Most family members reported that organ donation had given positive meaning to their loss. One mother seemed to speak for all family members when she explained that "organ donation brought a lot of joy. It made me feel good inside that I did something good for somebody... So that's a big relief to have something good come out of a devastating event." In fact, for two parents "organ donation was the only thing that gave [them] a bit of peace and comfort" (Pelletier, 1992).

## Discussion

Family members had to cope with the stress of life-threatening illness in their loved ones, the uncertainty of outcome, and the diagnosis of brain death. In response, they experienced overwhelming emotions and used a combination of seven types of coping strategies. Most sought information, emotional support, and escape-avoidance during the anticipation stage. Only one strategy, making the suggestion of organ donation, was used during the

confrontation stage. The finding that a variety of strategies were used by family members supports Lazarus and Folkman's (1984) premise that individuals cope in complex ways during a stressful event. However, it is also possible that they were having difficulty coping and were trying various strategies in an effort to find those that were effective.

Family members had a tremendous need to understand what was happening during the acute phase of the life-threatening illness. As found elsewhere (King, 1985; Bedworth & Molen, 1982; Cozac, 1988; King & Gregor, 1985), family members sought information from a number of sources. According to Lazarus and Folkman (1984), information is most actively sought when the uncertainty of an outcome is greatest. However, the findings of this study suggest that, although information seeking may have been a helpful coping strategy, it may also have contributed to distress. Although it increased their understanding, which reduced distress and stimulated consent to organ donation, when family members became aware of the irreversibility of the illness, this generated overwhelming feelings. This supports the premise that emotion and coping affect each other, with emotion both facilitating and interfering with coping, and coping either increasing or decreasing distress (Folkman and Lazarus, 1988).

Family members identified nurses as being genuinely sensitive to their need for informational and emotional support. Such interventions have been described by nurses as emotionally exhausting. However, the nurses' willingness to be involved with the family members is in keeping with the finding that most nurses perceive organ donation as an opportunity to help the grieving family find comfort and positive meaning in their loss (Bidigare & Oermann, 1991; Kiberd & Kiberd, 1992; Stoeckle, 1990).

Escape-avoidance patterns of coping like those observed in the current study have proven to be significantly helpful. This is especially true when a loved one's well-being is at stake (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986), or in situations that are emotionally distressing and appraised as unchangeable (Folkman & Lazarus, 1985; Lazarus & Folkman 1984), beyond the individual's control (Folkman et al., 1986; Folkman & Lazarus, 1988), or uncertain (Lazarus & Folkman, 1984). Bedworth and Molen (1982), King (1988) and Nyamathi (1987) also found that relatives of critically ill patients used avoidance during this period.

However, by both seeking information and escaping-avoiding, most family members were using contradictory coping strategies. Although they wanted to understand the implications of the life-threatening illness, they used escape-avoidance approaches to divert their thoughts away from the



situation. According to Folkman and Lazarus (1988), the use of contradictory coping strategies is especially helpful when neither strategy alone does not effectively help to master, reduce, or tolerate stressful situations. Alternately, if an escape-avoidance strategy helps to mitigate the emotional impact of seeking information, then their functions could be considered complimentary (Folkman & Lazarus 1988).

All seven families in the current study consented to organ donation; five of them requested organ donation and two readily consented when approached. This finding contrasts with those of Bartucci (1987), Fulton, Fulton, & Simmons (1977), and Morton and Leonard (1979), who found that all families were approached, and not all consented. In the current study, family members confirmed that discussion about organ donation before the tragic event made it easier to decide to donate. Factors that motivated family members to consent included: (a) a strong respect for the loved one's wishes to donate; (b) an unquestionable commitment to fulfill those wishes; and (c) a belief that organ donation could change the sudden loss of a loved one into something more positive. This supports Lazarus and Folkman's (1984) premise that commitment "can impel a person towards a course of action that can reduce threat and help sustain coping efforts" (p. 61). Our findings are in contrast with those of Fulton et al. (1977) and Morton and Leonard (1979). They reported that knowing that the deceased person wished to donate did not stimulate any families to suggest donation. The differences between these findings may be due in part to a recent increase in awareness of the positive effects of donation and transplantation (Pelletier, 1992).

In summary, although the family members' coping patterns resembled those of other families in similar situations, they differed from other donor families. In particular, six of the seven families in the current study had discussed organ donation before the event, which facilitated their decision to donate, and five families requested organ donation. Coping strategies helped family members, to make sense of the situation, deal with their emotions, and change the sudden loss into something positive.

### **Implications for Nursing**

This case analysis of coping strategies under catastrophic conditions can guide the development of individualized nursing interventions to enhance coping in similar circumstances. In order to help family members use effective coping efforts, nurses must understand the meaning that the event has for them. Assessments should examine family members' perceptions of the life-threatening situation, their fears, and their coping strategies. The nurse can help individual family members cope by (a) identifying ways they have coped in previous situations, and supporting the use of familiar strategies, (b) pro-

viding information about the range of strategies that they might use, (c) suggesting and facilitating the use of novel strategies and (d) encouraging the use of a variety of strategies.

According to Pittman (1985) nurses have a responsibility to extend such support to the family beyond the hospital setting. Through home visits or phone calls nurses can provide family members with the opportunity to ask questions and express concerns. In addition, such contact can provide nurses with the opportunity to assess family members' feelings about the loss, coping abilities, resumption of daily activities, support systems, and patterns of family interactions. This can guide the development of specific interventions to meet the family members' unique needs and enhance their ability to cope. By assessing and strengthening the family member's coping skills, nurses can empower them to deal with the complex processes of organ donation and bereavement.

In conclusion, Lazarus and Folkman's (1984) theory provided direction and understanding of how family member's of organ donors cope with the stressors and emotions experienced during the phases of organ donation. Furthermore, the theory allows nurses and other health care providers to appreciate the importance of evaluating coping in relation to the context in which it occurs.

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