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GUEST EDITORIAL

Confronting the Challenges, Capturing the Complexities

It is hard to believe that a year has passed since we all met in Montreal for the Third International Family Nursing Conference. The energy and enthusiasm generated during those days reaffirmed for many of us that assisting families to develop their health potential is indeed what nursing is all about. It was particularly exciting to see how far we had come in the development of the science of family nursing in the brief span of three years since our last get-together in Portland, Oregon.

Although we left the conference feeling justifiably proud of our accomplishments, we also left with a greater awareness of the many challenges still facing us, as practitioners, researchers and educators. In the articles devoted to Family Health in this issue, we see how our colleagues are addressing some of these challenges.

In her plenary address on the second morning of the conference, Cheryl Taylor challenged us to consider one of the major threats to family health, that of domestic violence. Have we as nurses heard and responded to this challenge? If we use as an indicator the number of papers presented at the conference on this topic and the frequency with which the issue of family violence appears in our nursing journals the answer to the question would have to be an unqualified "No". Ratner, however, in her article on *Indicators of Exposure to Wife Abuse* stresses that this is and must be a concern for nursing. Her findings that the status of marriage, family income, number of children in the family, and education of family members are associated with wife abuse, provide compelling evidence for a family-centered nursing approach.

Capturing the complexities of the family within a research framework is the challenge taken up by Gottlieb and Feeley, and Clarke. These authors focus our attention on some of the theoretical and methodological issues facing the "family nurse" researcher. They bring a new perspective on some "old" concerns and remind us that there is no substitute for careful and thoughtful decision making in the designing and conduct of family studies. Although other disciplines have grappled with some of these same issues, few researchers in family nursing appear to have taken on these challenges. Gottlieb, Feeley and Clarke's articles, therefore, fill a critical void.

Despite the progress we have made on many fronts, Duhamel questions whether or not the practice of family nursing really does exist and if not why not. In her Discourse on this subject, Duhamel proposes a number of factors that may account for the continuing gap between theory, research and practice.

In the remaining few lines of this editorial I would like to offer to the reader two more challenges, both of which are based on the premise that indeed nursing has a role to play in developing the health potential of families. The first and most fundamental of these relates to the ongoing need for evidence that we as nurses can and do "make a difference". From this follows the second challenge, that of influencing family health policy. I recently attended the Annual Research Day sponsored by the Faculty of Nursing at the University of Toronto. The day began with keynote addresses by Dean Dorothy Pringle and Dr. Ada Sue Hinshaw, each dealing with the question of the relationship between nursing research and health policy. As I listened to the remarks of these two speakers I could not help but reflect on the questions – Have we made a difference? and, What about our role as policy designers within the area of family health? Yes, perhaps our research findings have helped shape and even change nursing practice (although there is still much to do) – BUT – has our research influenced family health policy? Although not specific to family health, questions which Dr. Hinshaw posed to the audience such as – Have we made our research visible and available to policy makers? Are we at the policy table when matters of concern to us are being debated? – are ones which we who are committed to family health can no longer avoid. These are the *challenges* facing us – are we willing to *confront* them?

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Saisir la complexité des défis et les relever

J'ai du mal à croire qu'une année déjà est passée depuis notre rencontre à Montréal pour la troisième conférence internationale sur les sciences infirmières de la famille. L'énergie et l'enthousiasme qui sont nés pendant ces quelques jours ont confirmé à nombre d'entre nous que le fait d'aider les familles à jouir de la meilleure santé possible est véritablement l'essence des sciences infirmières. C'était en effet passionnant de voir la distance que nous avions parcourue dans le développement des sciences infirmières de la famille durant les trois courtes années qui s'étaient écoulées depuis notre précédente rencontre à Portland, Oregon.

Nous avons terminé la conférence légitimement fiers de ce que nous avions accompli. Cependant, nous avions également conscience des nombreux défis qu'il nous restait à relever en tant que médecins, chercheurs et enseignants. Le présent numéro traitant de la santé de la famille, nous constatons que nous sommes en train de relever certains desdits défis.

Au cours de son discours principal lors de la deuxième matinée de la conférence, Cheryl Taylor nous a priés d'examiner la plus grande menace à la santé de la famille, à savoir la violence conjugale. En tant qu'infirmières, avons-nous compris ce défis et l'avons-nous relevé? Si nous prenons comme indicateur le nombre d'articles présentés sur ce sujet à la conférence et la fréquence à laquelle la question de la violence familiale apparaît dans nos revues de sciences infirmières, la réponse est, sans détour, «non». Pourtant, madame Ratner, dans son article sur *Les indicateurs de la violence conjugale*, indique que c'est une question qui doit conerner les sciences infirmières. Ses consclusions qui font état du lien entre l'état matrimonial, les revenus de la famille, le nombre d'enfants dans la famille, le niveau de scolarité des membres de la famille, et la violence conjugale sont la preuve évidente que les sciences infirmières doivent adopter une démarche centrée sur la famille.

Mesdames Gottlieb et Feeley, et M. Clarke relève le défi qui consiste à saisir la complexité de la famille dans un cadre de recherche. Les auteurs attirent notre attention sur quelques questions théoriques et méthodologique auxquelles font face les chercheurs en sciences infirmières de la famille. Ils nous permettent de voir quelques «anciennes» questions dans une perspective nouvelle et nous rappellent que rien ne peut remplacer des décisions prudentes et réfléchies pour ce qui concerne l'élaboration et la mise en place de recherches sur la famille. Même si d'autres disciplines ont pu être confrontées à certaines questions identiques, peu de chercheurs en sciences infirmières de la famille semblent avoir tenté de relever ces défis. Ainsi, les articles susmentionnés comblent un vide important.

Malgré les progrès que nous avons accompli sur de nombreux fronts, madame Duhamel demande si la pratique des sciences infirmières de la famille existe réellement et, dans la négative, quelle en est la raison. Dans son discours sur ce sujet, elle énumère un certain nombre de facteurs qui pourraient expliquer l'écart entre la théorie, la recherche et la pratique.

J'aimerais enfin proposer à nos lecteurs deux autres défis, partant du principe que les sciences infirmières ont effectivement un rôle à jouer pour que les familles arrivent à jouir de la meilleure santé possible. Le premier et le plus important a trait à la nécessité de montrer qu'en tant qu'infirmières, nous pouvons faire et nous faisons une différence. De ce premier défi découle le second, à savoir influencer la politique de la santé de la famille. J'ai assisté dernièrement à la Journée sur la recherche annuelle parrainée par la faculté des sciences infirmières de l'université de Toronto. La journée commença avec les discours d'ouverture de la doyenne Dorothy Pringle et de la Dre Ada Sue Hinshaw. Chacun traita du problème de la relation entre la recherche en sciences infirmières et la politique de la santé. Tandis que j'écoutais ces deux orateurs, je ne pus m'empêcher de me poser les questions : «avons-nous fait une différence?» et «avons-nous rempli notre rôle de décideurs dans le domaine de la santé de la famille?» Il est évident que les conclusions de nos recherches ont peut-être aidé à façonner ou même changer la pratique des sciences infirmières (même s'il reste tant à faire). POURTANT, nos recherches ont-elles influencé la politique de la santé de la famille? Bien qu'elles ne s'adressent pas seulement à la santé de la famille, les questions qu'a posées la Dre Hinshaw telles «Avons-nous divulgué nos recherches dans le domaine de la santé de la famille et les avons-nous mises à la disposition des décideurs?» «Sommes-nous assis à la table des négociations lorsque tout ce qui concerne la santé de la famille y est débattu?» ne peuvent plus être éludées par nous qui sommes engagés pour la santé de la famille. Les *défis* sont bien là – allons-nous les *relever*?

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Discourse

The Practice of Family Nursing Care: Still a Challenge!

Fabie Duhamel

Undeniably, the family is an essential part of nursing care. The incidence of chronic illness is increasing and early discharge of patients from hospitals, as a result of health care reform, require families to assume more responsibilities for the care of their members. These families find themselves in need of the assistance and expertise provided by nurses.

Family nursing is becoming a flourishing domain. Over the last seven years, three international family nursing conferences have been held, the *Journal of Family Nursing* was born, and the study of families has been incorporated into many educational curricula (Wright & Bell, 1989).

Theoretical concepts of family nursing are indeed rapidly developing under the influence of various family-focused disciplines. Despite the noticeable progress in theory and research, as a clinician, educator and researcher, I am struck by the absence of family nursing within the practice arena. The implementation of the theoretical concepts in clinical practice is lagging behind. In too many clinical settings family nursing is almost nonexistent or developing very slowly. Several questions come to mind: Do nurses recognize the importance of the family in health and illness? Do nurses know how to acquire a better understanding of families' experiences and how to deal with them? How are nurses taught to provide family nursing? Do nurses provide the families with the appropriate care? Is it effective? How is it measured? In this discourse I examine some of the factors that may explain why family nursing care is not being reflected in practice.

Family Nursing Practice

There is an increasing number of nurses who are interested in the family's experience in health and illness and who are sensitized to the importance of family care. In many clinical settings such as perinatal, pediatric, and commu-

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nity health care, the family has traditionally been an integral part of nursing practice. Families have been considered the target of nursing and have been a valued partner in all aspects of nursing care.

However, the involvement of families has been slow to extend to other clinical areas. Sadly, in these areas, families remain invisible or still worse are considered a burden. All too frequently the solution to dealing with families has been to avoid them or refer their concerns and complaints to the head nurse or clinical nurse specialist.

Lack of time, knowledge and skills, are cited as the major factors impeding the quality of family nursing care. If these can be considered valid reasons, what are the implications for the educational preparation of nurses, nursing administration, and research?

Educational Preparation

In recent years, we have made much progress in the development of family nursing models. Different theories from the fields of family science and family studies (e.g., Systems Theory, Developmental Theory, Role and Family Stress Theories) and Family Therapy have served as the foundational base for family assessment and intervention models in family nursing (Friedman, 1992; Gottlieb & Rowat,1987; Wright & Leahey, 1994). These family nursing models are continuously being updated. Scholars propel the theoretical component of family care ahead but at a pace that is rapidly surpassing implementation in actual nursing practice.

Yet despite the existing knowledge, as an educator involved in graduate nursing education and in various educational activities in the clinical setting, I have observed that nurses lack the theoretical and clinical preparation to effectively practise family nursing. Why is this so? Do educational curricula offer adequate preparation for the practice of family nursing? It would appear the emphasis of nursing education at the college level is focused on the individual and to a lesser extent on the family. Thus, it is not surprising that these nurses have limited skills in how to nurse families. In a survey of Canadian University Schools of Nursing, Wright and Bell (1989) found that family nursing content was well incorporated in undergraduate programs. Yet, there was a dearth of content dealing with family assessment, intervention, and interviewing skills. Wright and Bell hypothesized that the difficulties of implementing family nursing care could be traced to the absence of these competencies. Thus, we need to ask ourselves whether our existing educational system lacks the appropriate teaching resources or skills to ensure the practice of this essential component of nursing care.

For family nursing to become a reality, the first step is that educational programs need to adopt family nursing as an essential part of the curriculum rather than as a "luxury". A case in point is at McGill University School of Nursing, where family care is an essential component of the McGill Nursing Model (Gottlieb & Rowat, 1987) and consequently is integrated throughout the undergraduate and graduate curricula. Thus, throughout the McGill affiliated clinical settings, a more family-oriented nursing practice can be observed compared to other non-affiliated clinical settings.

An alternative model to developing family nursing is that found at the University of Calgary and Université de Montréal where family care is considered a domain of nursing in which one can specialize and develop advanced practice at the graduate level. Family systems nursing is practised when the "family system" is the unit of care; the relationship between the family dynamics and the health issue is assessed and considered the focus of intervention. A family nursing unit has been created to teach family systems nursing. Faculty members demonstrate family interviewing skills and provide on-site supervision (Wright, Watson & Bell, 1990). In so doing, graduate students are more inclined to promote family nursing.

Administration

Most nursing administrators recognize the significance of family nursing but only a minority ensure its practice. Priority is given to physical nursing care often citing economic restraints and nursing workload as the rationale. What often is not recognized, however, even in terms of these very practical considerations, is the inherent potential within a family-centred approach for the saving of time and effort. Unfortunately there are few mentors, within the clinical setting, who have the knowledge and skills of working with families.

Without the support of nursing administrators in clinical settings the implementation process is near to impossible. Nurse administrators need to support nurses in their practice of family nursing by providing educational resources (mentors and inservice education).

Research

To what extent can the relative absence of family nursing care be attributed to the nature of our research? Does the nurse view the results of such research as irrelevant to his/her practice? Family nursing research in the main has consisted of descriptive studies of families` experiences in health and illness, with a focus primarily on single family members or dyads. Very few studies have looked at family interactions or the interplay of family dynamics and health/illness. Limited also are those studies that evaluate the effect of selected nursing interventions on family health (Bell & Wright, 1995).

One possible approach to reducing the distance between practice and research may be to increase the dialogue between clinicians, researchers, and families. Systemic and "post-positivist" thinking demand new strategies to foster the concept of partnership between the nurse and the family not only in theory and practice but in research endeavours. A shift from individual to interactional data in family research is needed and the adoption of a perspective which enhances the dimension of "belief systems","interactions", and "relationships" between family members themselves and between the nurse and the family.

We need to refocus our thinking in family nursing research from a linear perspective (one which perceives nursing intervention as doing something to the client), towards a circular perspective (one which views nursing interventions as occurring within the context of a therapeutic conversation with the client/family). Within such an orientation, the nurse and the client/family co-construct interventions through their interactions. The nurse and the client/family are both influencing and being influenced by the interventions they co-construct.

If the constructivist paradigm (Watzlawick, 1984) is embraced as a useful way for conceptualizing reality, then it invites a new mode of research and a new type of researcher. Different research methodologies are needed to address the notion that one's world results from social co-constructions (Furth, 1987) and the principle of mutual connectedness of the observer and the observed (Varela, 1979). We need to consider research strategies such as participative or "co-operative inquiry" in order to be more congruent with the new emerging philosophy in the nursing of families. If embraced, families, nurse-clinicians, and researchers would jointly participate as co-researchers and co-subjects in the development and evaluation of family nursing interventions. Could this joint venture in research promote partnership in nursing care? Could it empower the family in its responsibilities and decision making regarding health and caring for its members? Could it facilitate the practice of family nursing?

Conclusion

To promote the practice of family nursing we must reevaluate our educational, administrative and research strategies. We must demonstrate flexibility towards new paradigms of inquiry that are more congruent with complex human and social phenomena and develop new practices that evolve out of practice-based research and research-based practice. The effervescence in this very promising field of nursing will be ever more useful and powerful!

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Nursing Intervention Studies:
Issues Related to Change and Timing

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Les cliniciens et les chercheurs doivent faire face à divers défis pour ce qui concerne l'élaboration et la mise à l'épreuve d'interventions infirmières ou de programmes pour des enfants et leurs familles. Nombre de ces défis sont liés aux questions de changement et de son opportunité. Le présent article examine certaines des questions importantes qui doivent être prises en considération lorsqu'on conçoit et on évalue les interventions auprès de cette population particulière. Les exemples illustrant ces questions sont tirés d'une étude qui a testé l'efficacité d'une intervention infirmière (basée sur le Modèle de McGill de soins infirmiers) dont l'objectif est d'améliorer l'adaptation psychosociale des enfants atteints de maladies chroniques. Les auteurs estiment que le fait de considérer ces questions avec attention améliorera l'élaboration des études sur l'intervention, l'évaluation de leurs résultats, et contribuera également à une plus grande connaissance dans ce domaine.

A variety of challenges confront clinicians and researchers involved in developing and testing nursing interventions or programs for children and their families. Many of these challenges relate to the issues of change and timing. This paper discusses some of the critical questions that must be considered when designing and evaluating interventions with this particular population. Issues are illustrated with examples from a study that tested the effectiveness of a nursing intervention (based on the McGill Model of Nursing) in improving the psychosocial adjustment of chronically ill children. The authors propose that careful consideration of these questions will improve the design of intervention studies, the evaluation of their outcomes, as well as contribute to the development of our knowledge in this domain.

The issue of change is at the very heart of nursing practice and the conduct of nursing science. Nursing interventions are typically employed to help clients and families bring about a desired change. Evaluation studies seek to examine to what extent an intervention has resulted in the desired change in the target population (those individuals, families, communities to which the intervention is directed). Recent trends in health promotion intervention research indicate a broadening of focus to include not only changes in self (e.g., health behaviors and lifestyles), but also changes in environment (e.g.,

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physical, social, economic). How clinicians and researchers conceptualize change and change processes will shape the ways they choose to work with individuals and families and the methodologies we select to evaluate effectiveness.

Although change is ubiquitous, it often escapes scrutiny (Mahoney, 1991). Yet, such scrutiny of change in client outcomes is necessary in community nursing practice. Limited financial resources and the demand for evidence of the effectiveness and efficiency of health care services have resulted in the recognition that there is a compelling need for research assessing the impact of community nursing practice on client health outcomes (Barriball & Mackenzie, 1993; Goeppinger, 1988; Kristjanson & Chalmers, 1991).

When designing intervention studies, researchers and clinicians are faced with two major decision-making areas. The first concerns decisions related to change. Such questions need to be considered as: *"What are we trying to change?" "Whom are we trying to change?" "How does change come about?" "How can we determine that change can be attributed in part to the intervention?"* The second area concerns decisions related to the timing of the intervention. It is impossible for clinicians and researchers to consider change without confronting issues of timing. Timing is important as it relates to the design and implementation of the intervention and the measurement of its impact. The types of questions that need to be addressed here are: *"When should the intervention occur?" "How long does an intervention have to continue to effect long-lasting change?"* Another set of questions concerns timing as it relates to when outcome measures should be taken. Questions must be addressed such as: *"When can we expect change to occur?" "How long will the change last?"*

These were some of the questions that we confronted in designing a randomized control trial study to evaluate the effectiveness of a year long home-based nursing intervention to enhance the psychosocial adjustment of children with a chronic condition (Pless, Feeley, Gottlieb, Rowat, Dougherty, & Willard, 1994). The nursing intervention was guided by the McGill Model of Nursing (Gottlieb & Rowat, 1987; Kravitz & Frey, 1989). The major features that characterize this model include a focus on overall health rather than illness and treatment, on all family members rather than the patient alone, on family goals rather than on the nurse's, and on family strengths rather than their deficits. According to this model, nursing takes place within a collaborative relationship wherein both the nurse and family jointly assume responsibility. The nurse's role is to structure learning experiences that empower families and enable them to define their issues of concern and arrive at approaches to meet their goals.

The purpose of this paper is to identify some issues and challenges specifically related to change and timing that need to be considered in intervention research with children and families in the community.

Conceptual and Methodological Issues Involving Change

What are We Trying to Change? Understanding the Phenomenon.

The impetus for conducting an intervention study often comes about because clinicians and/or researchers identify an area in need of change and believe they know how to effect change. The first and most fundamental question that they must ask when designing an intervention study is: *What is the nature of the phenomenon that is being targeted for change?* The answer to this question is premised on theoretical understandings about the phenomenon targeted for change and knowledge about change and change processes. A thorough understanding of the phenomenon and its characteristics is required because certain phenomenon are more amenable to change than others, and different methodological implications will arise depending on the nature of the phenomenon. For example, specific behaviours such as children's temper tantrums might be more readily changed than children's shyness. Temper tantrums are shaped by the type and amount of positive and negative reinforcement given by parents and others, whereas shyness is a temperament trait that is genetically influenced.

A subset of questions that need to be addressed to clarify the researcher's understanding of the characteristics of phenomenon under study include: *What purpose does the phenomenon serve to the system's integrity and, or to its maintenance and organization? How does the phenomenon develop over time? How long has it been in place?* This knowledge will determine the type of change that can be expected and will help forecast how long the change should take to achieve. For example, phenomenon that involve core processes, such as the construction of self (self-esteem, identity), values (valence), reality (order), and power (control) are more difficult to change because they develop slowly, involve deep structural changes within the organism and system, and maintain the system's integrity (Mahoney, 1991). Thus, an intervention of short duration would be unlikely to alter a child's self-esteem. This implies that intervention studies that target core processes need to be long-term to effect any perceptible, long-lasting changes. The issue of length and intensity of an intervention will be further discussed in this paper.

Another characteristic to consider is the form the phenomenon takes at various phases of development. This is particularly relevant to the study of young children. The issue here is that the phenomenon of interest may exhibit itself differently at different ages, as it evolves and changes. For exam-

ple, if the researcher is interested in children's gross motor development, the researcher would observe turning and crawling in the infant, but with toddlers walking and running would be more appropriate indicators of gross motor development. Thus, the challenge is to determine what constitutes "same" but "analogous" behaviours across ages (Kessen, 1960). Consequently, when repeated assessment of the phenomenon are made over time as children grow and develop, different instruments may be required to measure the same phenomenon at different ages.

In our study, we assessed children's self-esteem with the Perceived Competency Scale for Children (Harter, 1982). Two different versions of this measure were used, one for children under 7 years of age, and another for children older than age seven. Harter developed these different versions because as children develop, their notion of self-esteem becomes more complex and differentiated. For example, in younger children self-esteem is manifested in four areas (maternal acceptance, peer acceptance, physical and cognitive competence), whereas for older children there are five specific domains of self-esteem (scholastic, athletic and social competence, physical appearance and behavioral conduct) and a general domain of global self-esteem.

The wide variability in the expression of the phenomenon of interest within age groups must also be considered. Variability can be affected by a multitude of factors such as genotype, gender, maturity determinants (e.g. taking on age-appropriate roles and responsibilities), cultural factors, co-occurrence of other life course events (e.g., entry to school), and social/contextual factors (i.e., support, poverty, maternal employment) (Aldous, 1990; Walsh, 1983). This underscores the importance of including control or comparison groups in order to attribute change to the intervention and not to the factors listed above as elaborated later in this paper.

Yet, another question that must be addressed concerns the purpose of the intervention. *Does the intervention seek to develop the phenomenon, change it, or maintain it?* This is an important distinction both for shaping the intervention and for determining the types of outcomes to measure. If the goal of the intervention is to develop a new set of behaviours, then the intervention should focus on helping parents and children acquire new knowledge and develop new skills. Prenatal classes and parenting programs are examples of interventions by community health nurses aimed at developing new knowledge and skills. When evaluating the effectiveness of the intervention, one would expect to find little evidence of the skill pre-intervention and some evidence of its development post-intervention. On the other hand, if the goal of the intervention is to change or alter a behaviour, the intervention may focus on extinguishing old behaviours, introducing new ones, and reinforcing them. For example, programs that are designed to alter unhealthy behaviours

such as behavioral training programs for parents who have abused their children (Wolfe & Wekerle, 1993) would fall within this category. The analyses would focus on examining patterns of change, and trends across time for the various behaviours. Finally, if the goal of the intervention is maintenance, the intervention would focus on support and reinforcement. Stability and consistency across time would be used as indices of maintenance.

Who are We Trying to Change? Deciding on Who to Target for Change

When working with children and families it is not always readily apparent who should be the focus of the intervention and subsequently the target of evaluation. In practice, community health nurses work at various levels of the family system and the larger environment to effect change. In designing a nursing intervention study, the researcher may decide to focus on: 1) individuals (i.e., mother, child), 2) subsystems (i.e., mother-child relationship), and/or 3) the family as a system, including their relationships with other social systems (i.e., extended family, health care system). Issues such as the knowledge of change and change processes, the potential differential rates of change among different family members, and who best can evaluate change need to be considered when making this decision.

Knowledge of change and change processes. It is important to understand the conditions that influence change in children and families and the mechanisms by which change takes place. These understandings usually derive from foundational knowledge about change and change processes. Researchers and clinicians need to articulate the theoretical bases of their perspective in planning and measuring change. For example, if the researcher subscribes to the theoretical position that the child is active and shapes the social environment (Sameroff, 1987), then the intervention would focus on the child only, and measures of change would focus on child outcomes. The child's social environment consists of the patterns of interactions and relationships that transpire between the child and other individuals. On the other hand, if the researcher subscribes to the belief that the child is a passive agent whose behaviour is shaped by the social environment, then the intervenor would elect to work with the mother alone to change the child's behaviour. Assessment, therefore, would be concerned primarily with child outcomes and secondarily with parent outcomes. However, if the researcher subscribes to a constructivist view of development (Mahoney, 1991; Scarr, 1992) in which both the child and the environment are active, responsive agents, the nurse would work with both the child and the mother. Changes in both the child and the environment would be the focus of measurement.

In our intervention study with chronically ill children and their families, we were concerned with affecting change in both the child and the family

environment. Hence, the nurses worked with the child, siblings, parents individually, and/or various dyads and triads within the family. There is empirical support for the effectiveness of such a multi-pronged approach to intervention. Reviews of the research on early childhood intervention programs and programs for maltreating parents have concluded that comprehensive interventions aimed at multiple levels of the child and family system are more likely to be most effective in bringing about the desired outcomes in child development (Seitz, Rosenbaum, & Apfel, 1985; Wolfe & Wekerle, 1993; Zigler, Taussig, & Black, 1992).

A second theoretical notion underlying our study as well as many models of family nursing is that of family systems theory. Family systems theory posits that each individual and subsystem within the family operates interdependently, influencing and being influenced by the others (Minuchin, 1985). Change in one part of a family system may affect the total system, as well as its subsystems (Mercer, 1989). Although an intervention may be targeted at one family member, change in the other family members and the system as a whole may also occur. For example, an intervention whose focus is on the child may result in unexpected changes at other levels of the system (Gray & Wandersman, 1980). To capture these unexpected outcomes, multiple measures should be employed within and across domains of potential health outcomes for different individuals and subsystems. To continue with the example from our study, we used several standardized measures of child, parent, and family outcomes to measure the a priori hypothesized mechanisms and outcomes. In addition, we included a qualitative component to capture the unexpected. We interviewed the chronically ill child's primary caregiver (usually the mother) to explore their perceptions about what changes had occurred and how these changes had come about (Ezer, Bray, & Gros, 1994). Mothers reported several outcomes that had not been captured with the standardized measures we had chosen. For example, they described the child taking more responsibility for the management of their chronic illness, gaining in self-confidence, and doing better in school.

Different Rates of Change Within Families and Between Families. Traditionally researchers have been concerned with measuring rates of change among different families. More recently attention has turned to examining rates of change within families. The impetus for this trend is the growing recognition that children, other family members, subsystems within the family, and the family system as a whole have their own developmental trajectory.

When families are being formed, experiencing novel events, or dealing with stressful situations, change will be more rapid because family processes (e.g., communication, decision-making) are being re-oriented and re-established. This implies that depending on the kind of change desired, the inten-

sity and the duration of nursing involvement required within families and across families may vary. When selecting an approach to intervening, the researcher should consider tailoring the intervention to the unique needs of each person and family. We will return to the issue of tailoring interventions later.

Who will assess change. An important decision that the researcher faces is who in the family will be asked to assess whether change has occurred. The most obvious choice is the individual targeted for change. However, in research with children and families this choice is not always straight forward because children are often too young to respond to self-report measures. In the past, research has relied on mothers' reports to assess change in their children, as well as change in the family (Ball, McKenry, & Price-Bonham, 1983) because of their intimate knowledge of family life, the amount of time that mothers spend with their children, and their availability to researchers. Although mothers' responses are important, theirs is just one of many perspectives on children and family life.

It has been commonly assumed that everyone in the family has one shared family environment and experiences that environment in the same way. However, recent empirical studies have pointed out that in fact this is not the case. Each family member has a different experience in their family and creates his/her own subjective meanings (Dunn & Plomin, 1990). For example, firstborn children have an inexperienced parent, whereas later born children have experienced parents. Moreover, each child has his/her own personality which may have a differential effect on how parents respond. These findings have important consequences for designing intervention studies. The implication of this principle is that the respondent must be kept constant across repeated measures. For example, in our study we were concerned with changes in the child's behaviour prior to and after the intervention. We asked parents to complete a standardized child behavioral checklist prior to the start of the intervention. If the mother completed the report at baseline and the father completed the assessment at the end of the intervention we excluded these data from the analyses because mothers' perceptions, and experiences may differ from those of fathers.

A second implication that arises as a result of the notion of non-shared environments concerns the use of multiple respondents. Traditionally, researchers have used triangulation as a test of the validity of a measure. Triangulation is a term that commonly refers to the use of multiple measures to converge on a construct (Breitmayer, Ayres, & Knafl, 1993). Nonetheless, other purposes for triangulation has also been described (Knafl & Breitmayer, 1989). Multiple respondents have been considered necessary in family research in order to capture the complexity of family systems and obtain a comprehensive view of the family (Moriarty, 1990). However, given our current

understanding, different family members' reports of the same phenomenon should be expected to diverge rather than converge. For example, when trying to assess how well children have done as a result of the intervention, the researcher may want to know whether change is apparent to both parents, as well as to those outside the family. She/he may also want to know whether the child's behaviour is consistent at home or at school. To this end, the researcher may elect to collect information about the child from the child him/herself, the child's siblings, peers, parents, teachers and anyone else of relevance. However, the researcher should expect moderate correlations among individuals because children's behaviour is fairly consistent, but there is variability within this consistency. Children and adults may respond differently in different situations with different people.

How Does Change Come About? Pathways Towards Change

Many evaluations of program effectiveness have failed to recognize that processes of development, individual differences in development, and environmental and contextual factors will lead to some children and families benefiting from an intervention, while others will remain the same, and some may even be harmed by it. Increasingly researchers are recognizing that the question is not just: "Does this intervention work?" but rather, *"What intervention works with who, in what domain of functioning and under what circumstances?"* (Dunst, Synder & Mankinen, 1989; Gray & Wandersman, 1980). Two approaches to data analysis may facilitate an understanding in this area: 1) an examination of overall group differences (between group differences), and 2) an examination of within intervention group differences through case or profile analysis (Bergman, 1992; Gray & Wandersman, 1980). These two approaches to analysis should complement each other.

Careful documentation of the intervention will allow the researcher to track the processes that occur during the intervention, and will also yield the data needed for the profile analyses that may provide important insights into why the intervention worked for some children but not for others. For example, in our study the first set of analyses examined the differences between children who received nursing care and those who did not with respect to child behaviour problems, role skills, and self-worth. In order to understand why and how some children benefited while others deteriorated over the course of the intervention, we conducted a profile-analysis. This was accomplished by compiling a profile of children's scores on many variables collected from many different sources (e.g., parent report on standardized measures, nurses' description of the each contact with the families during the course of the intervention, and parent interviews conducted post-intervention) (Gottlieb & Feeley, 1995). Improvement in child psychosocial adjustment was shown to be linked to the ability of the mother and or child to become

engaged in the intervention, the nature of the issues worked on, and the nurse's direct involvement with school-age children and adolescents.

How Can We Know that the Intervention Contributed to the Observed Change?

Although it is difficult to attribute change solely to the intervention, nonetheless there are research procedures, that if followed, allow the researcher to infer that some of the change can be attributed to the intervention. This issue is all the more salient in research with children. Because change occurs at a more rapid pace in children it is sometimes difficult to determine whether a change is due to another event occurring at the same time as the intervention, to the intervention, or to a naturally occurring developmental shift in the child (Rutter, 1983). To illustrate: After the birth of a second child, mothers commonly report an increase in toileting accidents in their preschool firstborns (Stewart, 1990). However, it is difficult to know if this is due to the preschoolers' way of dealing with the stress accompanying the sibling's birth or whether it is due to a natural lapse that is part of the course of toilet training.

The use of a control or comparative group is the most common strategy to address this issue. Control is particularly important to establish in the study of both children and families to counter the argument that change may have occurred as a result of maturation (Bailey & Simeonsson, 1986). In experiments, control is obtained through comparison of the participants who did and did not receive the intervention (Fugate-Woods, 1988). In addition random assignment of study participants to either the intervention or control group (a critical feature of experimental designs) reduces the likelihood of systematic bias in the two groups with respect to any variables that might be linked to the outcome of interest (Polit & Hungler, 1989). The groups that are formed following random assignment should be comparable with respect to a variety of background characteristics.

In the event that one cannot use a control group, then comparative groups are a reasonable alternative. When studying naturally occurring events, such as the birth of a sibling, it is impossible to randomly assign firstborns to families having a new baby, and those not. Instead, a comparison group can be selected from individuals known to be similar to those who will receive the intervention with respect to several pertinent characteristics that have been found to effect the phenomenon (Friedman, 1987). We will illustrate this point with an example of children's adjustment to a sibling's birth. In a second study undertaken by Gottlieb and Baillies (1995), the phenomenon under study concerned understanding firstborns' reactions during their mother's pregnancy. A group of only children whose mother was not pregnant served as the comparison. The comparison group was matched with the "pregnancy" group children on age, because age has been found to influence firstborns' reactions to a sibling's birth (Gottlieb & Mendelson, 1990).

In summary, before undertaking the design and implementation of an intervention study with children and families, nurse researchers and clinicians need to spend considerable time gaining a thorough understanding about the phenomenon they are trying to change and the processes by which change comes about. Only when one has acquired this understanding is one ready to proceed to decisions related to timing.

Conceptual and Methodological Issues Involving Timing

The issue of timing is critical to the design of intervention studies, particularly as it relates to the timing of the intervention and the measurement of outcomes. There are two specific questions that researchers need to examine: *"When to intervene?"* and *"How long an intervention should last?"* Underlying these questions is knowledge of when change is most likely to occur.

When to Intervene

Change is more rapid and more readily achievable during a critical period, such as when core processes are being laid down and, or transformed as in infancy, early childhood, and adolescence. Many early childhood intervention programs are premised on this assumption (Carnegie Corporation Of New York, 1994; Hamburg, 1992). Change is also more achievable during periods of transition, critical life events, or stressful experiences. This is not surprising in light of the theoretical understanding of what happens during these periods (Schumacher & Meleis, 1994). These events make new demands, which in turn cause major disruptions to individuals and families. To meet these demands individuals and families must master new ways of coping, redefine existing relationships, learn new roles, and/or restructure a different sense of self. In attempting to meet these challenges, individuals and families are more vulnerable and consequently more open to change at these times.

Therefore, transitions, critical life events or stressful experiences are important periods for growth. Nurses have a key role to play in promoting growth and change. If the goal of the intervention is to change core processes and develop new insights, knowledge, and skills, then these periods provide the best opportunity for entrée into the family. In our study, we decided to include families who had been living with the child's chronic condition for at least a year, and excluded those whose child had been recently diagnosed. Our choice may have made it more difficult to bring about change in child psychosocial adjustment because families had been living with the chronic illness for at least one year, and as many as fourteen years.

There is some empirical evidence to suggest that the timing of an intervention plays a role in the process of change. Larson (1980) found that the timing of a home visitation program for mothers was critical in effecting posi-

tive mother-infant outcomes. Mothers who began the intervention during their pregnancy benefited more than mothers who began in the postpartum period. This suggests that interventions aimed at effecting change may be potentially more effective at transitional periods in child and family development, such as the birth of the first child, or when a child enters school; or during stressful periods, such as the diagnosis of a chronic illness. Although theoretically this seems to be the case, there have been few systematic studies to support these notions. Kristjanson and Chalmers (1991) observed there is currently little knowledge in the community health nursing literature concerning the most effective timing of interventions with families.

Even during critical periods, change is a dynamic process punctuated by phases of change intermingled with periods of stability (Mahoney, 1991). In contrast to the view that change and continuity are distinct and independent constructs (Fawcett, 1989; Hall, 1981, 1983), we ascribe to the perspective that change and continuity are separate but integrally related, co-dependent constructs (Liddle & Saba, 1983; Mahoney, 1991). Mahoney (1991) argues that stabilizing processes are self-protective inasmuch as they enable the person or family to function in the face of new demands without disintegrating or becoming disorganized. For example, when a new child is born the change in the family roles and relationships will occur to in-corporate the needs of the new child. But at the same time the family will adhere to old patterns of functioning (e.g., maintaining usual daily routines).

The co-existence of change and self-stabilizing processes helps to explain why change is difficult to achieve. Despite the need for longitudinal research, granting agencies tend to favour short-term intervention studies. Researchers may be confronted with having to choose between intense interventions with a small number of families, and less intense intervention with a greater number of families (Gray & Wandersman, 1980). The aim of our study was to improve the psychosocial adjustment of children with a chronic illness and to prevent deterioration. We decided on a year long intervention because we recognized that the study nurses would require time to develop relationships with the families, and help families work on bringing about the change they desired. Furthermore, we were aware that some families would take more time to develop a relationship with the nurse, and some would be resistant to the nurses' efforts to develop a relationship.

Our understanding of the balance between the need to change and the need to stabilize implies that nurses have to be sensitive to people's energy levels and readiness to change. Interventions must be tailored to the needs of families. The McGill Model of Nursing (Gottlieb & Rowat, 1987) recognizes the importance of timing and pacing. Moreover, there is empirical support for this position. Interventions conducted with children and parents in early

childhood have been shown to be more effective when the intervention is tailored to the needs, values, interests, and readiness of the participants and/ or the community (Dunst, Synder & Mankinen, 1989). However, the clinical realities of timing potentially conflict with the imperatives of experimental designs. In spite of this understanding about change and stability, many disciplines, nursing included, still subscribe to the belief that a key to sound research design of intervention studies is the standardization of interventions (Edwards, 1993). Standardization means that all participants receive the same intervention, and is premised on the assumption that all individuals have the same needs and will respond in the same fashion.

One potential solution to this dilemma is to establish a "minimum" intervention and tailor further intervention to each family's needs. This was the method we employed in our study of families with a child with a chronic illness. The design called for a minimum number of contacts (one per month) that every family would receive regardless of need over the 12 month period (Pless et al., 1994). Additional contacts were scheduled based on families' needs. Each family, in collaboration with the nurse, determined the "dose" of nursing they received and set the agenda for their work together. To be able to attribute change to the intervention, the nurses documented the details of their nursing for each contact with the families. They maintained contact logs, which described who was present, how long the visit lasted, the location, and who initiated the contact. As well, they described the nature of families' concerns, goals and types of nursing strategies they used. This enabled us to describe the intervention in depth and to examine the effects of the actual intervention on outcomes (Gottlieb & Feeley, 1995). The advantage was that the researcher could examine what actually happened for each participant. These data were important for the profile analysis described earlier.

Another potential solution is that utilized by Webster-Stratton (1992) to evaluate the effectiveness of a parenting program for parents of children with conduct disorders (Webster-Stratton, 1984). Groups of parents view a predetermined series of videotape vignettes of parent-child interactions. Although the overall program format and content are standardized, the actual administration of the program centers on the interests and concerns of the particular group.

When an intervention is standardized, documentation can still be important. It cannot be assumed that the intervention will be the same for all participants, particularly when the intervention takes place in the home, or is delivered by several intervenors (Gray & Wandersman, 1980). A number of factors may contribute to variations in the intervention across participants. Thus, the researcher should acknowledge that there will probably be a discrepancy between the planned and actual intervention, and document as

completely as possible the actual intervention that participants received (Goeppinger, 1988). Mechanisms for documenting the intervention (such as those that we described in the example from our study) must be developed prior to beginning the intervention. The difficulty the researcher will encounter is that documentation and analyses of these data are time consuming and tedious for both the nurses and the researcher, and seldom considered worthwhile by funding sources.

How Long Should the Intervention Last?

How long does an intervention have to be to effect long-lasting change? How frequent should it be? These questions underlie decisions about the intensity of the intervention. Researchers have little empirical data to guide them in answering these questions as little is known about what "dose" of community nursing intervention is required to bring about change (Kristjanson & Chalmers, 1991). Research is needed to address this issue. However, knowledge of change processes suggests that an intervention needs to be of reasonable duration to bring about change, and should include "boosters" of the intervention (Clarke & Clarke, 1989). The effects of short-term early childhood interventions seem to fade, while more successful programs provide intervention over time, supporting the child and their family through various phases of development (Zigler, Taussig & Black, 1992). There is some evidence that more intense interventions (high contact over a relatively short period of time) may be more effective. As a result, models currently in use in the domain of infant mental health and psychiatry advocate intensive work with the mother and child (Emde, 1988).

When Should Change be Measured?

Another aspect of timing that needs to be considered is when to measure change and then how to determine whether its effects are long-lasting. Although we suggested earlier that it may be best to intervene at the time of a transition, critical life event, or stressful experiences; this may not be the best time to assess the outcomes of an intervention. Rather, the researcher should assess outcomes once the transition has been completed. A thorough understanding of the phenomenon of interest will be helpful. Specifically, knowledge of the time table under which events unfold is needed to decide when to assess change. Good descriptive studies of developmental transitions, life event trajectories, and the development of phenomenon of interest to nurses are needed. Although there is great variability among individuals, the outer ranges of behaviour can be determined. For example, women between the ages of 18 and 45 are considered to be best equipped to meet the challenges and demands of motherhood. Currently, there is debate about the desirability and impact of a woman having a baby at 13 or 60.

Intervention studies typically assess change at just one point in time, usually immediately following the nursing intervention. The problem with this practice is that researchers may fail to observe change that has yet to emerge (Type II error), or may detect change that is only transitory (Type I error). Only repeated observations of sufficient duration after the completion of the intervention and replication studies will answer questions concerning the permanency of change.

Nurse researchers often expect short-term effects from any intervention. However, some have noted that this may be highly unrealistic, especially in infancy and early childhood when the effects of intervention may not be stable (Emde, 1988). The possibility of delayed effects must also be considered in the design of intervention studies with children and families in the community. Developmental psychologists have become increasingly aware of the possibility of sleeper or delayed effects from follow-up studies of early child intervention programs (Emde, 1988). One major problem has been obtaining the funds for follow-up assessments. Furthermore, it may also be difficult to assess how long follow-up is required (Emde, 1988).

A case to support the need for multiple points of measurement of change is the study by Stein and Jessop (1991). At the end of the intervention, children who received the year long home care intervention were better adjusted than children in the control group who received routine care. In a five year follow-up study, the investigators found that the psychosocial adjustment of children who received the intervention continued to improve, while children in the control group remained stable. Thus, the gap between children who received the intervention and those that did not grew over time. Without these repeated measurements, the long-term effects of intervention would have gone undetected and the impact of this intervention would have been undermined.

Conclusion

The past two decades of research have yielded rich descriptions of many nursing phenomena. As nursing develops, the discipline will continue to require this descriptive work. Nonetheless, in some domains nurses have accumulated sufficient knowledge to guide work with clients and families to bring about desired changes. As Ellis argued, nursing is a practice discipline and needs to conduct investigations that will improve practice and the knowledge upon which practice is based (Pressler & Fitzpatrick, 1988). Furthermore, as nursing moves forward in this decade of increasing accountability, there will be mounting pressure to demonstrate the outcomes and effectiveness of our nursing. In response to these forces, nurses are already encountering evidence of a growing number of intervention studies. This avenue of research will yield knowledge about how to work with children and families, and the effectiveness of approaches with whom and when.

As more researchers embark on this path, they need to pay heed to some of the fundamental questions raised here. Although the issues and questions we have raised are particularly salient when conducting research with children and families, many are highly relevant to the study of adults as well. While we have proposed answers to these questions, it can be anticipated that other nurse researchers' experiences will provide different answers and raise other questions. It is imperative that clinicians and researchers share their questions, insights about change and approaches to the assessment of change with others. Only then will new methodological knowledge and new approaches to the designing and conduct of intervention studies emerge.

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Acknowledgements

Indicators of Exposure to Wife Abuse

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On a analysé les données collectées au cours d'une interview au téléphone auprès de 406 femmes mariées, sélectionnées de façon aléatoire (y compris les conjoints de fait) en suivant trente indicateurs potentiels de violence conjugale. Les femmes qui ont rapporté qu'elles avaient subi de la violence conjugale au cours de l'année précédente étaient, plus souvent que les femmes qui ne subissaient pas de violence conjugale, susceptibles d'avoir mis un terme à leur mariage, d'être allées aux urgences, d'avoir été hospitalisées ou d'avoir pris contact avec une infirmière de la santé publique, un psychiatre ou un psychologue au cours de l'année passée. Dans la plupart des cas, elles avaient souffert de larges ecchymoses, des déchirures, des entorses ou des foulures. Elles avaient eu des maux de tête et de dos, elles avaient souffert d'états morbides et d'alcoolisme plus souvent que les femmes ne subissant pas de violence conjugale. Les femmes battues étaient souvent plus scolarisées que leur partenaire, leurs revenus de ménage étaient relativement moins élevés et leur partenaire était souvent au chômage. Connaître les indicateurs significatifs peut faciliter l'identification des femmes subissant des violences conjugales et peut conduire à l'élaboration de protocoles de traitement de signalements plus efficaces.

Data collected via a telephone survey of 406 randomly selected married (including common-law) women were analyzed with respect to 30 potential indicators of exposure to wife abuse. Women who reported exposure to wife abuse within the previous year were more likely than women free of abuse to have terminated their marriage, to have visited an emergency room, to have been hospitalized, and to have contacted public health nurses, psychiatrists, and psychologists, in the preceding year. They also were more likely to have sustained large bruises, lacerations, sprains or strains, and to have more frequent headaches and backaches, psychiatric morbidity, and alcoholism than women free of abuse. The abused women were likely to have more education than their partners, relatively lower total household incomes, and partners who were unemployed. Knowledge of significant indicators can facilitate the identification of women who have experienced wife abuse and lead to the development of more effective screening protocols.

In 1992, the Canadian Nurses Association published "Family Violence: Clinical Guidelines for Nurses" in an attempt to inform nurses and dispel commonly held myths about family violence, and to provide direction for nursing practice in a variety of clinical settings. Included in the publication are "examples of indicators of family violence" (p. 8) that nurses are advised to be familiar with in order to identify victims, even those who do not present as obvious cases. Nurses are provided with examples of "family violence screening questions" (p. 8) to incorporate into their assessment procedures, and are advised to explore with all clients the potential of violence. There is an underlying theme that certain factors should heighten nurses suspicion that family violence has occurred. For example, the authors suggest that victims may suffer from nutritional deprivation, sleep deprivation, emotional trauma, neglected follow-up for Pap smears and breast lumps, untreated sexually

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transmitted diseases or yeast infections, and frequent premature discontinuation of antibiotic therapy. The authors also describe "abuse indicators for women," including injuries to bones or soft tissues, bruising to the abdomen, breast or perineum, particularly if the woman is pregnant, bite marks, unusual burns, frequent visits to health facilities, depression, miscarriages, and poverty.

Stark and his colleagues claimed there is a definite pattern in the characteristics of women who have been abused (Stark, Flitcraft, & Frazier, 1979; Stark et al., 1981). In particular, they claimed that abused women could be readily identified by the presence of characteristic injuries: those that can only be sustained in an assault, that cannot be explained by, or is inconsistent with, the immediate alleged etiology, that involve more than one anatomical site, and that involve the face, neck, chest, breasts or abdomen. They further reported that abused women use medical emergency services more frequently than those who are not abused; may often complain of "symptoms without evidence of physiologic dysfunction" (Stark et al., 1981, p. 28), such as headaches or nonspecific muscle pain; and frequently use tranquilizers, sleep medications, and alcohol. Other descriptive studies suggest that abused women may sustain fractures—particularly to the nose, ribs, jaw, and arms—multiple contusions, lacerations, burns, and head injuries (Appleton, 1980; Gayford, 1975; Rounsaville, 1978; Rounsaville & Weissman, 1978). Additionally, Haber (1985) and Haber and Roos (1984) reported that approximately one-half of the women who presented to a chronic pain centre had a history of physical and/or sexual abuse. All of their problems with pain, including back pain and headache, reportedly followed the first incident of abuse.

On the other hand, other studies have concluded that there are no characteristics that differentiate women who are abused from women who are not (Council on Scientific Affairs, 1992), and therefore no risk markers for women who are more likely to be assaulted by their partners (Hotaling & Sugarman, 1986). The findings related to alcoholism among abused women remain equivocal: some have indicated that abused women are more likely than non-abused women to be alcohol-dependent (Bergman, Larsson, Brismar, & Klang, 1987; Hillard, 1985; Stark et al., 1979); others have failed to confirm this (Appleton, 1980; Bullock & McFarlane, 1989; Van Hasselt, Morrison, & Bellack, 1985)

Hotaling and Sugarman (1990) concluded that "little heuristic value can be gained by focusing primarily on the victim in the assessment of risk to wife assault" (p. 12). They examined those factors that are possibly causal in nature or precursors to wife abuse without examining the sequelae or consequences of wife abuse. They may be correct in suggesting that characteristics of victims cannot help us explain why abuse occurs, but outcomes of wife

abuse may help health professionals identify victims who have not sought help. Conversely, if indicators are unlikely to differentiate abused women from non-abused women, health professionals may be placing too much emphasis on injury and other health problems as important assessment tools.

Several studies have provided evidence that abused women suffer from depression, anxiety, and low self-esteem, and may attempt suicide (Cascardi, Langhinrichsen, & Vivian, 1992; Sato & Heiby, 1992). Their mental health is reportedly poorer than that of women free of abuse (Aguilar & Nightingale, 1994; Jaffe, Wolfe, Wilson, & Zak, 1986; Kérouac, Taggart, Lescop, & Fortin, 1986), and they are more likely to be prescribed medications, particularly anxiolytics, sedatives, and anti-depressants (Dobash & Dobash, 1979; Stark et al., 1979; Tearmann Society for Battered Women, 1988). Several investigators have reported that a significant proportion of the women who attend emergency rooms are abused within their intimate relationships (Appleton, 1980; Goldberg & Tomlanovich, 1984; McLeer & Anwar, 1989; Rounsaville, 1978; Rounsaville & Weissman, 1978; Tilden & Shepherd, 1987), but their use of other health care services has been less well studied. Brismar, Bergman, Larsson, and Strandberg (1987) found that the health care consumption by abused women in Sweden was considerably greater than that of non-abused women. Similarly, Stark et al. (1981) reported that, at one hospital, the psychiatric emergency service was used by five times as many abused as non-abused women and 77% of the visits to the women's clinic were made by abused women.

Purpose

There is a paucity of empirical evidence supporting the claim that particular "screening questions" or "abuse indicators" are valid assessment tools in the identification of women who have been exposed to family violence. The purpose of the current research was twofold: first, to identify indicators of exposure to wife abuse or violence in the form of bodily aggression; second, to take a first step toward generating a predictive model of exposure to wife abuse. Such a model could include the potential outcomes of abuse (indicators of exposure to wife abuse) as well as risk markers or precursors of abuse, and could serve as the basis of a screening protocol.

The research to date on this subject suffers from several significant limitations: much of it is descriptive or exploratory in nature with little reference to comparison groups, for the most part, it has used convenience samples of women residing in emergency shelters or attending emergency rooms, and it has paid little attention to the health care utilization patterns of women who experience wife abuse. In the current study, we attempted to address some of these gaps: we surveyed a community-based, random sample of women, whereby we could compare abused and non-abused women.

Method

Sample

Data were collected from a probability sample of married women (including those in common-law relationships), 18 years of age or older, who were currently living with, or had in the previous year lived with, a male partner in the city of Edmonton, Canada. Subjects were selected using a random-digit dialing method (Lalu, 1991), and of 557 women who met the eligibility criteria, 406 (72.9%) agreed to participate (Ratner, 1991, 1993).

Procedure

The author conducted 20-minute telephone interviews to ascertain the annual cumulative incidence of wife abuse, associated health problems and health care utilization patterns, and socio-demographic characteristics of the women and their partners. Smith (1989) found that telephone and face-to-face surveys of wife abuse compare favourably, including considerations of the representativeness of the sample and the quality of the data. Respondents were informed of the purpose of the study, and that they had the right to refuse to participate, refrain from answering any questions, or terminate the interview at any time.

Brush (1993) argued that the most significant threat to the validity of surveys on wife abuse is the "context of the interaction between interviewer and interviewee" (p. 249). She claimed that it was essential to infuse trust, safety, and intimacy into the interviewing relationship. Although the current study was limited by the context of an anonymous telephone call, such an infusion was made possible by the fact that all interviews were conducted by one female interviewer (the author) who is knowledgeable about and sensitive toward the issue of wife abuse. The interviewer ensured the safety of the respondents and stayed on the line for as long as respondents wanted to discuss their experiences. Women who seemed distressed or reported abuse were referred to appropriate support services.

On the basis of empirical evidence, it has been suggested that the 30 variables included in the current analysis are possible indicators of exposure to wife abuse. The variables assess the nature and extent of injuries sustained, the presence of headache or backache, alcoholism, psychological health, prescription drug use, health service utilization, and selected personal characteristics of the abused wife or her male partner. These variables may indicate precursors of wife abuse or aid in the identification of victims. They may form the basis of an effective screening mechanism suitable for all health care settings.

Instruments

Most of the variables examined in the current analysis were measured via single-item indicators. Psychiatric morbidity was assessed by responses to the 28-item General Health Questionnaire (GHQ) (Goldberg & Hillier, 1979), with items scored on a 4-point response scale from *not at all* to *much more than usual*. The recommended (0-0-1-1) scoring method was employed and dichotomized responses were summed; total scores of 5 and greater were considered indicative of psychological illness or psychiatric morbidity. Using this scoring method, the GHQ has a reported sensitivity ranging from 80% to 92%, a specificity ranging from 89% to 92%, and an 8% to 14% overall misclassification rate when contrasted with psychiatrists' clinical assessments (Goldberg & Hillier, 1979; Rabins & Brooks, 1981). Concurrent validity coefficients, correlating the GHQ with psychiatrists' ratings of their structured interviews have ranged from .70 to .83, and a split-half reliability coefficient of .78 has been reported (Vieweg & Hedlund, 1983) (.71 in the current study). The depression and anxiety subscales of the GHQ correlated from .75 to .87 and .43 to .83, respectively, with the Leeds Scales, self-assessments of depression and anxiety in women who recently suffered the death of a baby (Forrest & Gerg, 1982). Construct validity of the subscales has been supported by factor analysis (Goldberg & Hillier, 1979).

Alcoholism was assessed with the CAGE (an acronym based on the key words *Cut down, Annoyed, Guilty,* and *Eye-opener*) (Ewing, 1984), a screening tool consisting of four questions about covert problem drinking. An affirmative response to two or more questions indicated alcoholism. The sensitivity and specificity of the CAGE were found to range from 75% to 93% and 76% to 96%, respectively, in comparison to a diagnosis of alcohol abuse based on the Michigan Alcoholism Screening Test (MAST), a detailed chart review, and an analysis of the quantity of alcohol consumed (Bush, Shaw, Cleary, Delbanco, & Aronson, 1987); against a standardized test of excessive drinking defined as more than 16 drinks per day (Bernadt, Taylor, Mumford, Smith, & Murray, 1982); and against interview responses regarding the quantity and frequency of alcohol intake (King, 1986). Concurrent validity coefficients comparing the CAGE with the Clydebank Questionnaire and the brief MAST in a community sample were .77 and .57, respectively (Saunders & Kershaw, 1980).

Exposure to wife abuse was measured with the 19-item Conflict Tactics Scales (CTS), Form N (Straus, 1979) of psychological and physical aggression used or experienced in conflicts with a partner. Three subscales (reasoning, verbal aggression, and physical aggression) comprise the scale, but in keeping with the adopted definition of wife abuse, only items related to physical aggression were included in the current analysis. Women were defined as physically abused if they reported exposure to one or more of the physical

aggression items within the previous year. The internal consistency (Cronbach's α) of the CTS has ranged from .80 to .83 (.80 in the current study) and item-total score correlations range from .70 to .87 (McFarlane, Parker, Soeken, & Bullock, 1992; Straus, 1979). Concurrent validity has been established by comparing different family members' reports of domestic violence and by comparing CTS scores with in-depth interview data (Browning & Dutton, 1986; Gelles, 1972; Straus, 1974; Straus, Gelles, & Steinmetz, 1980).

The data regarding physical health problems—including backache, headache, and injuries, prescription drug use, health care service utilization—and socio-demographic information were generated from items constructed by the author, and where possible, were derived from national surveys. The three questionnaires and the single-item indicators were pretested on a sample of 25 women.

Analysis

Each of the 30 study variables (see Table 1 for listing) was evaluated with respect to its relationship to exposure to wife abuse. For these bivariate analyses, contingency table methods ($\chi 2$ tests) were used, unless the variable was continuous, in which case Student's *t*-tests were carried out. We then attempted to reduce the number of variables to a smaller subset to develop a predictive model; only those variables most associated with the outcome of interest were included. Models that are parsimonious are more likely to be numerically stable and are more easily generalized (Hosmer & Lemeshow, 1989).

The entire set of 30 variables was then entered, en bloc, in an initial logistic regression model. The importance of each variable was verified by examining the Wald statistic, which compares the maximum likelihood estimate of the slope coefficient (β) to the estimate of its standard error ($SE(\beta)$), and by comparing the estimated coefficient with the coefficient from a bivariate model containing only that variable. Variables that did not contribute to the model were eliminated and a new model fit. This process was repeated with each new model compared to the old model through the likelihood ratio test until a model that contained only the essential variables was obtained. The selection of the essential variables was verified by repeating the model building process using stepwise logistic regression with forward selection and backward elimination with a criterion for entry of $p < .05$ and for elimination of $p > .10$.

Once the essential variables were determined, the need for interaction terms was examined by adding variables to the model that were equal to the product of the values of two of the essential variables. The process was repeated until all possible, plausible interactions were evaluated. The continuous scaled variables were checked to ensure that they were linear in the logit

(the logit is the logarithmic component of the logistic model that represents the ratio of frequencies of the two different outcomes: abused and non-abused in this model [Last, 1988]). No adjustments to the model were found to be necessary.

The overall fit and adequacy of the model were assessed. Summary measures of goodness-of-fit, including the Pearson Chi-square statistic, the deviance, and the Hosmer-Lemeshow test statistics (C), were calculated to summarize the agreement of observed and fitted values. Other logistic regression diagnostics were carried out to determine that fit was supported over the entire set of covariate patterns: the leverage values, the influence values, and changes in the value of the Pearson Chi-square statistic with deletion of covariate patterns were plotted against the estimated probabilities. Those covariate patterns with large values on one or more of the diagnostic statistics were examined to determine whether their observed exposure status was different than expected and to assess the influence they had on the model.

Results

Of the 406 respondents, 81.5% were married, 13.5% were living in common-law relationships, and 5% had become separated, divorced or widowed within the previous year. The mean age of the respondents was 39.4 years ($SD = 14.3$; range: 18-82). The relationship of interest had persisted an average of 14.5 years ($SD = 13.6$; range: <1-55 years). The women had an average of 1.8 children ($SD = 1.4$; range: 0-10) with 1.1 children currently in residence ($SD = 1.1$; range: 0-5). The majority (60.7%) were employed outside the home, and the median level of education attained was a completed high school diploma. The results from seven women were eliminated from the logistic regression analysis due to missing data.

Forty-three (10.8%) women reported physical abuse perpetrated by their male partners in the previous year. Table 1 indicates the relationship between each of the potential indicators and reported exposure to wife abuse within the previous year. The average age of non-abused women was 40.5 years; that of women who reported abuse was 30.1 years. Also, women who reported that they were free of abuse were likely to have been married longer than those who reported abuse ($M = 15.4$ years versus $M = 6.6$ years, respectively). Women who were abused also had more children residing with them ($M = 1.7$) than women free of abuse ($M = 1.1$). The state of a woman's marriage (whether ongoing or terminated) was highly related to whether she had been exposed to wife abuse in the previous year: wife abuse was reported by 8% of women whose marriages continued, versus almost 71% of women whose marriages had ended in the previous year.

Table 1

Indicators of Exposure to Wife Abuse ($N = 399$ interview respondents)

Variable	Coding	No. of Women	No. abused (%)	χ^2
State of Marriage	Continued	383	31 (8.1)	59.9***a
	Ended	17	12 (70.6)	
Unemployed	No	269	25 (9.3)	1.4
	Yes	131	18 (13.7)	
Partner Unemployed	No	370	33 (8.9)	14.8***
	Yes	30	10 (33.3)	
Education	< High School	83	12 (14.5)	1.5
	High School	129	13 (10.1)	
	Postsecondary	187	18 (9.6)	
Partner's Education	< High School	70	10 (14.3)	1.1
	High School	131	14 (10.7)	
	Postsecondary	187	18 (9.6)	
Disparity in Education[b]	≤ Education	278	24 (8.6)	4.2*
	> Education	109	18 (16.5)	
Wife's Income	< $10,000	152	17 (11.2)	1.2
	$10,000-$19,999	101	14 (13.9)	
	≥ $20,000	111	10 (9.0)	
Combined Income	< $30,000	104	18 (17.3)	9.1*
	$30,000-$49,999	146	18 (12.3)	
	≥ $50,000	100	4 (4.0)	
Visited ER in Past Year	No	314	26 (8.3)	8.1**
	Yes	86	17 (19.8)	
Public Nurse Contact in Past Year	No	287	22 (7.7)	9.0**
	Yes	113	21 (18.6)	
Psychiatrist Contact in Past Year	No	381	35 (9.2)	17.1***
	Yes	19	8 (42.1)	
Hospitalized in Past Year	No	322	28 (8.7)	6.2*
	Yes	78	15 (19.2)	
Psychologist Contact in Past Year	No	366	33 (9.0)	11.4***
	Yes	34	10 (29.4)	
Sustained Large Bruises in Past Year	No	168	10 (6.0)	6.1*
	Yes	232	33 (14.2)	
Laceration with Sutures in Past Year	No	382	38 (9.9)	4.0*
	Yes	18	5 (27.8)	
Sprain or Strain in Past Year	No	302	25 (8.3)	6.8**
	Yes	98	18 (18.4)	
Frequency of Headaches	Never/Rarely	141	7 (5.0)	12.7**
	Occasionally	147	15 (10.2)	
	Frequently	11	121 (18.9)	
Headache Intensity	Slight/Mild	107	8 (7.5)	2.9
	Moderate	174	19 (10.9)	
	Severe	101	15 (14.9)	
Frequency of Backaches	Never/Rarely	161	13 (8.1)	6.5*
	Occasionally	128	11 (8.6)	
	Frequently	111	19 (17.1)	

A woman's employment outside the home, her income, her education, and her partner's education were unrelated to wife abuse. However, disparity in education was related to abuse; women with more education than their partners were more likely to report abuse (17%) than those with equivalent or less education (9%). Women whose partners were unemployed were more likely to report abuse (33%) than those whose partners were employed (9%). Women who reported gross combined incomes of more than $50,000 annually reported less abuse (4%) than those who reported $30,000 to $49,000 (12%) or less than $30,000 (17%).

Several indicators of health and health care were found to have significant relationships with exposure to wife abuse: significantly higher levels of wife abuse were reported by women who had attended an emergency room (ER) within the previous year (20%) versus (8%), or who had had contact with public or community health nurses (19%) versus (8%). Also, exposure

Table 1 (continued)

Variable	Coding	No. of Women	No. abused (%)	χ^2
Backache Intensity	Slight/Mild	149	12 (8.1)	4.5
	Moderate	143	21 (14.7)	
	Severe	45	8 (17.8)	
Tranquilizers Taken in Past Month	No	375	38 10.1)	1.7
	Yes	24	5 (20.8)	
Psychotropic Drugs Taken in Past Month	No	342	34 (9.9)	1.6
	Yes	58	9 (15.5)	
Alcoholism (CAGE)	No	380	36 (9.5)	10.4**
	Yes	20	7 (35.0)	
Psychiatric Morbidity (GHQ)	No	258	10 (3.9)	34.9***
	Yes	139	33 (23.7)	

Variable	Non-Abused Women M (SD)	Abused Women M (SD)	t (df)	p
Age	40.5 (14.5)	30.1 (6.8)	8.0^c (97)	< .001
Years in Relationship	15.4 (13.9)	6.6 (5.1)	8.3^c (138)	< .001
Number of Children at Home	1.1 (1.1)	1.7 (1.2)	3.6 (398)	< .001
Number ER Visits in Past Year	0.3 (0.9)	0.9 (1.3)	2.8^c (47)	.008
Number Public Health Nurse Visits	0.7 (3.1)	1.7 (2.8)	2.1 (398)	.04
Number of Days in Hospital Past Year	1.2 (6.2)	3.0 (8.0)	1.4^c (48)	.17

a   Yates Correction factor used in all 2 x 2 analyses.
b   Woman's education relative to her partner's.
c   Unequal variances; separate t-test formula used.
*p < .05. **p < .01. ***p < .001.

to wife abuse was reported by 42% of women who had seen a psychiatrist, 19% who had been hospitalized for any reason, and 29% who had seen a psychologist within the previous year. These reported rates of wife abuse were all significantly higher than those for women who did not have such health care contacts.

Women who reported specific injuries within the previous year, including large bruises, lacerations requiring suturing, and sprains or strains, were more likely to report wife abuse. The frequency of headaches and backaches were positively associated with reported abuse. Abuse was reported by 19% of women who experienced frequent headaches versus 5% who rarely or never experienced headaches, and 17% of women who experienced frequent backaches versus 8% who rarely or never experienced backaches. The intensity of headache or backache was not associated with reported abuse.

Psychiatric morbidity (non-psychotic psychiatric illness, including anxiety and depression) and alcoholism were associated with exposure to wife abuse. Almost 24% of the women with psychiatric morbidity reported being abused, compared to 4% who were free of morbidity. Thirty-five percent of women who suffered alcoholism reported abuse, compared to approximately 10% who were free of alcoholism. The use of psychotropic drugs (including antidepressants, tranquilizers, and sleeping pills) or tranquilizers alone was not associated with the reporting of abuse.

According to the logistic regression model (Table 2) women whose marriages had ended within the previous year had a 7.3 times greater chance (odds ratio) of having been abused within the previous year than women whose marriages continued, after controlling for the other six variables in the model. Women who had seen a psychiatrist within the previous year were 6.9 times as likely to have been abused as women who had not seen a psychiatrist, when the other key variables are controlled.

A goodness-of-fit test of the model was carried out, based on the procedure developed by Hosmer and Lemeshow (1989). The observed numbers of women who were and were not abused were compared to the expected numbers using the model and a high level of fit was found ($C = 6.55$, $p = .59$) [$\chi^2 (391, N = 399) = 327.26$, $p = .99$; deviance = 170.51]. Although not an indicator of the fit of a model, the adequacy of a model's ability to correctly classify cases according to the outcome variable can also be assessed. The overall classification of this model was 93% using a cutpoint of .50. Sensitivity and specificity were 44.2% and 98.9%, respectively. The positive predictive value was 82.6% and the negative predictive value was 93.6%. Thus, some cases and their respective covariate patterns were not well fit by the model.

Table 2

Multivariate Logistic Regression Model of Indicators Associated with Exposure to Wife Abuse

Variable	β	SE(β)	Odds Ratio	95% Confidence Interval
Age[a]	–0.10	0.029	0.91	0.86–0.96
Number of Children	0.62	0.186	1.85	1.29–2.66
Laceration	1.76	0.685	5.83	1.52–22.34
Partner unemployed	1.81	0.578	6.10	1.96–18-95
Psychiatrist	1.93	0.697	6.90	1.76–27.06
Psychiatric Morbidity	1.56	0.439	4.78	2.02–11.29
State of Marriage	1.99	0.674	7.28	1.94–27.26
Constant	-1.26			

a Odds ratio for age based on 5-year reduction is: 1.64 (1.23, 2.18).

Discussion

The odds ratio estimates and associated confidence intervals of the final model show that the seven variables in the model are strongly associated with the reporting of exposure to wife abuse. However, several additional variables such as ER visits, public/community health nurse contacts, psychologist contacts, and hospitalizations, were found to be strongly associated with reported wife abuse on bivariate analysis. Rather than being irrelevant, these variables may have been only marginally inferior to those included in the model, and unnecessary given the other variables in the model. It is possible that other variables or combinations of variables could result in an equally well-fit model. In addition, some of these variables were presumably incorporated in the variables included in the model. For example, contact with psychologists is likely subsumed by psychiatric morbidity and visits to an emergency room are likely subsumed by lacerations that require suturing.

In a review of 52 studies Hotaling and Sugarman (1986) evaluated 97 potential indicators of wife abuse and made an important contribution to our understanding of indicators. They concluded that women's income, education, and employment status do not discriminate wife abuse victims from non-victims. Similarly, the current study found these variables to be unrelated to wife abuse. However, it has consistently been found that age is associated with wife abuse; younger women are more likely to report victimization (Gaquin, 1977; Gelles, 1972; Stark et al., 1981; Straus et al., 1980). In contrast with Hotaling and Sugarman's conclusion that alcohol usage was consistently unrelated to wife abuse, our study revealed that it was. Shields and Hanneke (1983), Stark et al. (1979), and Telch and Lindquist (1984) also reported greater use of alcohol among victims of wife abuse. The use of psychotropic drugs or tranquilizers was not found to be associated with wife abuse. Other

studies are equivocal on this possible association. Of five studies reviewed by Hotaling and Sugarman, three reported a significant association between drug usage and wife abuse victimization (Coleman, Weinman, & Hsi, 1980; Semmelman, 1982; Stark et al., 1981).

Findings related to the characteristics of abusive husbands remain inconsistent. Hotaling and Sugarman (1986) found that although several studies reported a negative relationship between a man's level of education and the likelihood of wife abuse, "the two most representative samples do not support this finding" (p. 113) (cf. Hornung, McCullough, & Sugimoto, 1981; Van Hasselt, Morrison, & Bellack, 1985). The results of the current study also concur with this. Hotaling and Sugarman uncovered only two studies that reported an association between unemployment among men and wife abuse (Peterson, 1980; Straus et al., 1980). Their cutoff criteria for a consistent marker were that it must be measured in at least three independent investigations and found to be significant in at least 70% of studies. In light of this and the findings of the current study, unemployment among men can be considered to be associated with wife abuse.

Four variables included in this study are characteristics of the couple: the status of the marriage, the combined or family income, the number of children residing at home, and disparity in education between the spouses. All were found to be associated with wife abuse: women whose marriages had ended within the previous year, and those with family incomes of less than $30,000 per annum, relatively more children at home, and more education than their partners were most likely to report abuse. Hotaling and Sugarman (1986) also reported that women whose marriages had recently ended and those with a lower family income or social class reported consistently higher rates of wife abuse. However, in a subsequent study, Hotaling and Sugarman (1990) suggested that the relationship between socioeconomic status and wife abuse is debatable. In their four-group analysis of variance, "socioeconomic status did not discriminate between physically assaulted wives and non-physically assaulted wives; however, lower socioeconomic women were more likely to be severely assaulted" (p. 10). They did not find the number of children in a family to be a significant marker of wife abuse. Finally, Hotaling and Sugarman (1986) concluded that educational disparity within the couple was an inconsistent marker, citing four studies that found a positive association and two that did not. In light of the current findings, educational disparity where the wife has a higher level of education than the husband can be considered to be associated with wife abuse.

Almost all of the variables related to health care utilization and health problems, included in the current study were associated with wife abuse. Stark et al. (1979, 1981) similarly concluded that abused women can be dis-

tinguished from non-abused women by the frequency, anatomic location, and types of injuries they sustain. Other investigators have reported that abused women are at higher risk for depression, anxiety, and somatization (Jaffe et al., 1986; Kérouac et al., 1986), and are relatively greater consumers of health care than non-abused women (Brismar et al., 1987; Stark et al., 1981).

In the current cross-sectional survey it was not possible to discern the temporal relationship of the variables of interest. However, it is likely that many of the variables in the model (e.g., the occurrence of lacerations, visits to a psychiatrist, psychiatric morbidity, and the state of the marriage) are likely to be sequelae of wife abuse. The purpose of the current study was to assess precursors or consequences of exposure to abuse rather than to test etiologic hypotheses or to identify causal factors of wife abuse. Although such knowledge cannot contribute to our understanding of the causes of wife abuse or to the identification of women who are at high risk but as yet free from wife abuse, it can facilitate effective screening of victims.

The model developed in the current analysis has a sensitivity of 44% and cannot be advocated as a screening tool; more than half of abused women would remain undetected. However, these findings lend support to the claim that there are indicators that can facilitate the identification of women who have experienced wife abuse. Knowledge of these and discovery of other indicators can lead to the development of more effective screening protocols and result in an elevated index of suspicion when a practitioner is in contact with a woman with the relevant characteristics. Such knowledge may prompt further investigation from practitioners who otherwise may be unwilling or unlikely to screen for abuse. To date, instituting standardized screening protocols has resulted in reported identification rates of 23% to 30% (McLeer & Anwar, 1989; Tilden & Shepherd, 1987). If health care professionals are to meet the challenge of effectively assisting women who are abused, a higher proportion of the victims must be correctly identified.

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Acknowledgements

Methodological Commentary

Characteristics of Families– Implications for Statistical Analysis in Family Nursing Research

Sean P. Clarke

Research dealing with family phenomena of concern to nursing carries inherent methodological challenges, due in large part to special characteristics of families as social units (Copeland & White, 1991; Daly, 1992; Larzelere & Klein, 1987). Shared history and close contact between family members result in measures obtained from more than one member of the same family being statistically dependent. However, families are composed of distinct individuals and measures from different family members cannot be collapsed or "averaged" without losing important data about each person's unique experience. Perceptions and beliefs of family members are strongly influenced by individual values and by roles in families (determined by age, gender, generation, and family history). Also, families adapt and evolve over time. Describing the shape and determinants of change in families is a priority, but measuring change remains very difficult. Since families are embedded in larger social systems, complex methods of data collection and analysis are often required to capture the reciprocal influences of the environment, the family, and the individual on each other. While these aspects of families have implications for all phases of the research process, many of these characteristics pose major challenges for statistical analysis (Schumm, Barnes, Bollman, Jurich, & Milliken, 1985).

Some family researchers have turned to special analysis techniques, for example path analysis and structural equation modeling (LISREL), to assist them in making causal links and verifying theories (Biddle & Marlin, 1987). Ultimately, clinicians and policymakers look to nursing research for answers about which factors are associated with (and perhaps even causally related to) desired or undesired outcomes for families. Testing propositions of emerging theories of family adaptation is a major goal in family nursing research (McCubbin, 1991). The "softness" of the variables many family researchers work with, and the impossibility of manipulating most family conditions experimentally, interfere with conclusively linking variables, yet methods like structural equation

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modeling are far from simple solutions to these problems (Biddle & Marlin, 1987; Cliff, 1983).

Statistical analysis is often seen as a matter of applying mathematical manipulations to data sets in a objective manner in order to arrive at unambiguous answers to research questions (Hornstein, 1988). The truth, however, is that data analysis involves an extensive set of subjective decisions regarding which statistical techniques to use, which variables to analyze, how these variables should be selected and possibly transformed for analysis, and how the results should be interpreted. Making sound choices in data analysis requires a familiarity not only with the practical aspects of statistics, but also an understanding of common issues in data analysis in one's field. Equipped with both of these types of knowledge, the nurse researcher can make informed choices about statistics throughout the planning and execution of a study. In this paper, some statistical implications of research involving three aspects of family phenomena will be discussed.

To provide a running example of choices in statistical analysis available in family research, reference will be made to Stewart's (1990) longitudinal study of family adaptation prior to and following the birth of a second child. Stewart and his colleagues followed 41 families over a 15-month period. Interview questions, pencil-and-paper questionnaires, and observations of family interactions were used to assess various dimensions of family adjustment including parental stress and responsibility for household and child-care tasks. Stewart's work is notable for its strong theoretical base (i.e. family systems theory and McCubbin and Patterson's Double ABC-X model of family adaptation) and innovative data collection techniques, as well as the proficient use of statistical analysis. The study is also of particular interest to family nursing research because Stewart's aim was to capture healthy family functioning and adaption and because Stewart, like many family nursing researchers, chose to gather a large amount of data from a relatively small sample of families.

Statistics and Selected Features of Families

Complexity of Family Phenomena

Family phenomena, like many objects of study in the social sciences, have a wide range of possible inputs, outputs, causes, and effects (Blalock, 1979). An obvious example is family adaptation to normative events and stressors, which research and clinical experience has demonstrated to be influenced by a wide range of factors (McCubbin, 1991). Often, family researchers measure a multiplicity of variables and attempt to determine the effects of these variables on a given individual or family outcome. Indeed, Abell (1990) mentions that some researchers and critics believe that family research studies are only worthwhile

when all aspects of families, family members and the environment are taken into account.

When the research question involves testing a set of relationships amongst a large number of the variables simultaneously, path analysis and structural equation modeling are often used. Outcome variables and variables believed to represent determinants of those outcomes are clearly set out, and the literature and clinical experience are used to justify all the hypothesized connections between variables. Unfortunately, when these approaches are chosen, there are serious consequences to not including variables known to influence a given phenomenon: "...without an attempt to include every relevant cause of an endogenous variable in the model ..., the estimates of relationships that are included in the model are biased [erroneously estimated]." (Godwin, 1988, p. 919) Specifically, this means that the magnitude and direction of relationships between variables may be incorrectly depicted if important variables are left out (Schumm, Southerly, & Figley, 1980). Clearly, the researcher must make a careful compromise between including "all" variables and selecting an insufficient range of variables, if and when complex family phenomena are studied using these statistical techniques.

A major drawback of selecting multivariable methods is that sample sizes required for analyses to provide stable and meaningful results increase with the number of variables included, and tend to be quite large (Tabachnick & Fidell, 1989). In structural equation modeling, usually data from a minimum of 150 to 200 subjects must be included, depending on the exact model being tested (Lavee, 1988). Clearly, considerable planning and expense are involved in data collection on this scale, and samples of this size may not be available to the nurse researcher. There are also other built-in limits to using these techniques to expand the number of variables that can be tied together in any single analysis. These limits are created at least partially by statistical aspects of the methods themselves, which restrict the kinds of variables (level of measurement, statistical distributions, and measurement assumptions) that the methods can accommodate, and (even in 1995) by limitations on computing power available to the researcher (Copeland & White, 1991; Teachman & Neustadtl, 1993).

LISREL and related methods are not the only statistical means of capturing complex relationships in family research. In Stewart's study, at least three major areas of family adaptation preceding and following the birth of a second child were of interest: parental stress and use of social support, household and child-care responsibilities, temperament of all members of the family, and adjustment of the firstborn child. Measures tapped a wide range of family unit characteristics and family member experiences: for instance, mothers' stress levels were believed to be related to demographic and overall family situation

characteristics, stressful life events, stressors related to the child and the infant, and social support. Stewart obtained many of these measures five times from as many as three members of each of the 41 families studied. With a sample size of 41, only a handful of variables could have been processed together in a multivariate regression analysis to determine their associations with an outcome variable.

However, methods that predict outcomes from background variables would have been inconsistent with the family systems theoretical framework grounding Stewart's study. Stewart sought to detect patterns of stability and change in family variables. Differences in measures between parents and across time, for instance, were analyzed using repeated-measures univariate analysis of variance (ANOVA) on a variable-by-variable basis. When possible associations between social support and reported stress were investigated, Stewart used canonical correlation, a technique that reveals overlap in statistical variation between groups of variables. In this particular case, one group was a set of measures of stress related to oneself, the firstborn child, and the infant, and the second set contained measures of social support. Handling the many variables included in the study, either one at a time or in groups, provided Stewart with the means to paint a very detailed picture of stability and change in the families he studied. Stewart selected subsets of variables and did not attempt to enter all variables in statistical models simultaneously. Cohen (1990) recommends a similar scaling back of the number of variables used in any given analysis, and cites clearer, more readily interpretable findings as a strength of such an approach.

If determining the predictive power of background variables had been considered important, there would have been at least one other analytic possibility to accommodate large numbers of variables. At least some of many variables in Stewart's study were highly intercorrelated (as we shall discuss next). The number of variables from the data set used in individual analyses could probably have been reduced by the analyst (using knowledge of the subject area) or through various statistical techniques (including factor analysis) (Fisher, Terry, & Ransom, 1990). Subsequently, small groups of independent and dependent variables could have been run through multiple regression or other statistical procedures.

Reciprocity of Family Relationships

Because family members have sustained involvement with each other and often share a common history and environment, measures using the same instrument taken from members of the same family are often highly intercorrelated. This creates at least two statistical issues. When two or more scores on the same instrument from different family members (for example mother's and

father's mood) are used as independent variables in a model to predict an outcome, if these variables are highly intercorrelated (bivariate r's above .80-.90), the results of many multivariable methods will be misleading and statistical packages may not be able to compute the parameters in the requested models at all (Tabachnick & Fidell, 1989). This problem is known as multicollinearity.

Secondly, shared variance in scores between members of the same family complicates the issue of trying to detect differences in these scores. If, for example, the means of statistically-dependent variables are compared using analysis methods that assume the variables are statistically independent, the chances of correctly identifying differences in responses between family members are reduced. This is due in part to the fact that independent groups comparison methods partition the variance in values differently than repeated-measures methods. Ball, McKenry, and Price-Bonham (1983) emphasize that values on the same instrument from members of the same family are indeed repeated measures of the same "subjects" and that repeated-measures (within-subjects) approaches are the appropriate techniques for comparing variables in within-family designs.

In Stewart's (1990) study, one of the major goals was to determine whether the experience of stress and of social support was comparable in husbands and wives, whether the sharing of household tasks changed over time, and whether behaviours engaged in by mother and father in interacting with the firstborn child changed over time. A wealth of data was collected from both mother and father using the same instruments around these areas. Stewart's main analytic approach was, consistent with Ball, McKenry, and Price-Bonham's recommendations, repeated-measures ANOVA using not only time of measurement, but also parent (mother versus father), as within-subjects factors.

Again, Stewart's aim was not to demonstrate which variables were statistically-significant predictors of individual or family outcomes. If prediction had been a goal in his study, highly-intercorrelated measures could not have been used as independent variables in the statistical models tested. Measures from different family members would need to be aggregated or discrepancy scores would need to be computed (Ferketich & Mercer, 1992), or a single member's score on the measure for each family would have to be selected. The technique chosen would be determined largely by considerations about which of these methods would use the information from the set of variables in the most meaningful way (Copeland & White, 1991).

Circularity of relationships between variables: Determining the direction of relationships

Systems theory is a major force in the development of theory and clinical practice in family nursing. Major elements of family systems theory include

propositions that relationships between family variables are complex, inter-twined, and characterized by multiple feedback loops. According to family systems theory, families are more than the sum of their parts, and there are no simple relationships where one or more family variables relate to each other through a single line of influence (Fisher, Terry, & Ransom, 1990; Stewart, 1990). Ecological perspectives proposing that families are embedded in larger social systems, and that families and the environment have reciprocal influ-ences on each other, have also been very influential in family nursing (Bron-fenbrenner, 1986).

Feetham (1990) is among the many authors who have commented that linear, additive statistical models cannot address the complex, multidirectional relationships that emerge from family systems theory. Since the researcher's analytic plan must be consistent with the theoretical framework guiding a particular study (Schumm, 1982), family nursing researchers must give considerable thought to the relationship of statistical analysis to the theoreti-cal assumptions driving their studies.

As was stated previously, determining causes and consequences of vari-ous aspects of family adjustment is a major thrust in family nursing research. However, as numerous philosophers of science have shown, causation is ex-tremely difficult to prove (Baumrind, 1983; Cliff, 1983). Baumrind (1983), borrowing from other authors, defines minimal criteria for causation: statistical association between variables, an appropriate temporal relationship between them (events cannot precede their putative causes), and, most importantly, the successive elimination of competing causes for the relationship between the variables. Certainty regarding the effect of variables on a family phenome-non is derived from a coherent pattern of results. In the words of John Tukey, the distinguished statistician:

> Causation can only be established as a theoretically inevitable conse-quence of empirical observations. Failure to recognize this dual requirement leads to asking too much of statistics and to consequent dissatisfaction. (Tukey, 1986, p.309).

Stewart's study was explicitly guided by family systems theory. He addressed the issues of circular relationships and causality in presenting both the framework for his study and his results. Distinctions between causes and effects were not made, and as noted before, shared variance between variables and differences in variables across spouses and over time were the major trends evaluated. Scores on the wide range of instruments used were first treated as independent variables, and then were subsequently treated as depen-dent variables in later analyses. Based on similarities and differences in these family variables, as well as changes in these variables over time, Stewart demonstrated that the birth of a second child is experienced differently by

husband and wife and proposed mechanisms that explain both the use of social support and possible changes in family roles during this transition.

Although Stewart provides an excellent example of how complex family data sets can be analyzed in a manner congruent with systems theory, it should be noted that other researchers have been able to reconcile testing linear models involving dependent and independent variables with a family systems approach. Accepting the inherently reductionist nature of quantitative research, they believe that one can examine small portions of the multidirectional webs linking family variables while acknowledging that the reality of family life is far more complicated (Abell, 1990; Fisher, Terry, & Ransom, 1990). Tests of linear relationships (for example, using multiple regression procedures), interpreted in the proper context, can provide the researcher with the pieces needed to construct richly-textured and highly complex pictures of family phenomena.

Path analysis, and later structural equation modeling (LISREL and related techniques), were at one time widely thought to provide researchers with a means of confirming theoretical models involving complex interrelationships and drawing conclusions about causality. Mulaik (1993), among other writers, reminds us that the results of any multivariate analyses can be read in many different ways. The consistency of a set of parameters with a particular theoretical interpretation does not prove that this interpretation reflects an underlying truth. Plausible alternative explanations for the connections between variables are rarely ruled out by any single analysis, whether a path analysis or not. Therefore, to speak of the results of any path analysis, or LISREL model as anything more than consistent with a given theory is highly misleading (Baumrind, 1983; Biddle & Marlin, 1987; Cliff, 1983; Lavee, 1988). Harsh criticism has led to a justified hesitation to associate the terms "causal" and "confirmatory" with such forms of analysis (Baumrind, 1983).

Nonetheless, path analysis and LISREL modeling remain powerful tools for knowledge-building since they allow probing of interconnections in data sets as well as the possibility, when properly used, of illuminating the directions of relationships between variables. These approaches are also often consistent with systems theory. For instance, Stewart himself recommended that some form of path or causal analysis be used to further assess some of the relationships brought out in his study. The family nursing researcher needs to be aware of the strengths and limitations of these methods.

Conclusion

The nature of families and family variables must be taken into careful account when researchers plan the analysis phase of their studies. When considering using multivariable techniques to capture the complexity of family phenom-

ena, it should be remembered that simple statistical methods that handle variables individually or in pairs, instead of in large groups simultaneously, can often portray this complexity quite well (Schumm, 1982). Handling variables that are measured in more than one family member requires careful thought, due to the statistical dependence of such measures and the problem of multicollinearity if these variables are entered into multivariable models together. Increasing the number of useful, supported theories in family nursing will require more than highly technical statistical methods that provide global tests of complicated interrelationships and verify causality only in a very weak sense. Families are not simply another type of social group. Family nurse researchers should be familiar with statistical aspects of describing family form and functioning, and should strive to understand the assumptions, strengths and limitations of the breadth of existing statistical techniques well enough to make informed decisions and choices in their studies (Brogan, 1989; Teachman & Neustadtl, 1993).

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Acknowledgement

Les représentations du sida en rapport à la santé et à la maladie chez des hommes québécois d'orientation homosexuelle vivant avec le sida

Marjolaine Bellavance et Michel Perreault

Cette étude explore les représentations sociales du sida, au Québec, en utilisant le cadre théorique des représentations sociales de la santé et de la maladie de Herzlich (1969). Une analyse inductive des verbatim recueillis auprès de huit homosexuels québécois atteints du sida a mis en lumière les diverses conceptions de la santé et de la maladie qui coexistent dans leurs représentations à mesure que la maladie leur fait traverser un processus évolutif. En présentant le phénomène du sida à partir du point de vue d'hommes qui en sont atteints, cette étude démontre que la santé et la maladie sont des construits sociaux qui permettent à l'infirmière de comprendre la façon avec laquelle les personnes donnent un sens à leurs états de santé et de maladie. De plus, les représentations sociales de la santé et de la maladie sont des indicateurs importants précisant la démarche de l'infirmière qui vise à accompagner les personnes atteintes du sida vers un changement de comportements et d'habitudes de vie qui soient générateurs de santé, même à travers la maladie.

Herzlich's (1969) theoretical framework was used to explore Acquired Immune Deficiency Syndrome (AIDS) from the point of view of affected individuals. Content analysis was performed on transcripts of interviews with eight French Canadian gay men living with AIDS. Results indicate that health and illness are socially constructed concepts and that health can coexist with illness. The authors discuss how Herzlich's framework can be used by nurses to better understand the individual's experience of illness and to guide the individual towards making behavioural changes that will generate health throughout the course of the illness.

Comprendre le sens de la maladie et son influence sur sa vie peut être thérapeutique puisque cette démarche permet de faire face aux situations tout en conservant le sentiment de sa propre identité ainsi que ceux d'appartenance sociale et de compréhension de ses pairs (Benner et Wrubel, 1989). Qu'en est-il avec le sida? Quel est le sens de la maladie pour des homosexuels vivant avec le sida? Que peut représenter la santé dans un contexte où la maladie mène à une mort inéluctable?

Pour examiner ces questions, le cadre théorique des représentations sociales de la santé et de la maladie de Herzlich (1969) a été utilisé auprès de huit homosexuels québécois. Peu connues des sciences infirmières, ces repré-

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sentations possèdent leur logique propre «sans référence à leur vérité médi-
cale» et influencent l'expérience de santé et de maladie de la personne malade
(Doise, 1986; Herzlich et Pierret, 1984). Ainsi, Jodelet (1989) a montré que les
habitants d'une petite communauté française se représentent la maladie men-
tale comme contagieuse. Ils croient éviter d'être contaminés par des personnes
psychiatrisées placées dans des familles d'accueil en évitant de manger dans l'as-
siette de ces «fous» et en ne lavant pas leur linge dans la même eau que la leur.

Reconnaissant l'importance des phénomènes représentatifs communé-
ment appelés «savoirs naïfs» ou «savoirs de sens commun» dans les échanges
sociaux et le développement de la science (Farr et Moscovici, 1984; Herzlich,
1969, 1972; Herzlich et Pierret, 1984; Jodelet, 1993a, 1993b; Moscovici, 1969,
1972, 1989), les représentations constituent une organisation d'ensemble des
notions d'opinions, d'attitudes, d'images, de croyances et de perceptions avec
lesquelles elles sont souvent confondues (Jodelet, 1993a; Moscovici, 1969).
Elles ont leurs origines dans des courants de pensée véhiculés à la fois par
l'interactionisme symbolique, l'ethno-méthodologie et la phénoménologie
(Berger et Luckman, 1966; Cicourel, 1973; Schutz, 1962; cités dans Jodelet,
1993a). Ces représentations sont dites sociales parce qu'elles contiennent à la
fois l'expérience personnelle et le bagage culturel (Jodelet, 1993a, 1993b).

Herzlich (1969) a dégagé dans les années 60 les représentations de la
santé, de la maladie, et de leurs rapports, chez des français de classe moyenne
et élevée, à partir d'entrevues en profondeur auprès de 80 personnes dont 24
% se disaient malades, 13 % disaient avoir été grandement malades, et 20 %
avaient eu un ou plusieurs accidents. Ces représentations ont trait aux con-
duites du bien-portant et du malade. Selon ces représentations, l'individu
dont la santé est acquise à la naissance livre une lutte continuelle au mode de
vie, générateur de la maladie. Le mode de vie désigne le cadre spatio-temporel
dans lequel la personne évolue ainsi que le rythme de vie et les comporte-
ments quotidiens qu'elle adopte. Perçu par la personne comme lui étant
extérieur, le mode de vie constitue une contrainte imposée à laquelle il faut
résister ou s'adapter. Les représentations de la santé et de la maladie se vivent
à la fois comme multiplicité et unité : on peut être malade dans la santé et on
peut être en santé dans la maladie.

La santé est intrinsèque à l'individu. Elle peut être vue (Herzlich, 1969)
comme un capital acquis, révélateur de la robustesse du corps et de son potentiel
de résistance aux maladies : c'est le fond de santé. La santé peut être aussi con-
sidérée comme une simple absence de maladie et n'est alors perçue que lors-
qu'on ne l'a plus. C'est la santé-vide. Enfin, la santé peut être représentée comme
une expérience positive dont on a pleinement conscience en raison du bien-être
corporel et fonctionnel que l'on éprouve. Elle devient une norme qui permet
de déduire si on est en santé ou si on est malade. C'est la santé-équilibre.

Selon Herzlich (1969), la maladie résulte de l'action du mode de vie. Même si l'individu y joue un rôle, ce mode de vie provient de l'extérieur. Il existe trois représentations de la maladie qui tournent autour de l'inactivité et qui se décrivent en termes relationnels et pas du tout biophysiologiques, au contraire de la représentation médicale de la maladie. On se représente la maladie comme maladie-destructrice quand l'inactivité, amenée par la maladie, implique l'abandon du rôle professionnel et familial et la destruction des liens avec son réseau social. Elle prend le sens d'une «désocialisation» dans laquelle il y a dépendance. Par contre, l'inactivité qu'impose la maladie peut entraîner une lutte pour préserver son intégrité physique et psychologique en ayant recours aux services de santé, ce qui nécessite une préparation et un apprentissage. C'est la maladie-métier. Au contraire, l'inactivité peut être vécue comme un allégement des charges, un abandon des responsabilités, une libération de ses obligations sociales. La maladie est alors perçue comme un enrichissement de la vie de la personne qui découvre des possibilités nouvelles de liberté et d'actualisation de sa personnalité. Il s'agit alors de la maladie-libératrice, troisième représentation possible de la maladie.

Peut-on retrouver ces mêmes représentations de la santé et de la maladie auprès de personnes aux prises avec la maladie caractéristique des années 80-90 qu'est le sida?

Méthode

Pour répondre aux questions de recherche, un devis de type qualitatif avec échantillon théorique a été utilisé. L'échantillon est composé d'hommes québécois, de langue maternelle française, de la génération des 30 ans, qui se disent homosexuels et qui vivent avec le sida. Le terme génération est entendu ici comme génération sociologique, en ce sens que les personnes qui y appartiennent partagent le même vécu social : valeurs, croyances, événements politiques et économiques. Ces hommes ont été recrutés et rencontrés dans une Unité hospitalière de recherche, d'enseignement et de soins sur le sida (UHRESS), où ils étaient hospitalisés (4) ou en fréquentaient les services ambulatoires (4). Un guide d'entretien a servi d'aide-mémoire et de guide d'écoute pour une entrevue semi-structurée, en profondeur, d'une durée d'une à deux heures, selon l'état du participant.

Analyse des données

Les données obtenues par une transcription *verbatim* sur support informatique ont été soumises à une analyse de contenu. Le texte de deux entrevues sélectionnées par les auteurs a été décomposé en utilisant chaque phrase et en donnant un nom à chaque événement ou idée. Ce premier codage a servi à rassembler les données brutes pour permettre une description précise des caractéristiques significatives du contenu. Des catégories reliées à la question

de recherche ont été établies en se basant sur le cadre théorique des représentations sociales tel que présenté par Herzlich (1969) et ont permis d'explorer les définitions et les classifications du sida ainsi que les conditions de la personne qui vit avec cette infection. Certaines sous-catégories ont été ajoutées lorsque les concepts identifiés n'étaient pas inclus dans le cadre théorique, mais ces concepts étaient toutefois appuyés par la documentation scientifique. Telles que suggérées par Holsti (1969), ces catégories sont une classification des concepts et visent à être exhaustives et indépendantes afin de refléter la validité de l'analyse des concepts et la fiabilité des jugements des chercheurs. De plus, elles tendent à être homogènes, pertinentes, objectives et fidèles (Bardin, 1977). Les autres textes ont été analysés en utilisant la même démarche. L'analyse de l'apparition (occurrence) de certains éléments a permis d'obtenir une première image du contenu et d'en différencier les grandes lignes. L'analyse de l'apparition simultanée (cooccurrence) de deux ou plusieurs éléments a mis en relief la présence ou l'absence de liens entre eux.

La vérification des données a été réalisée par des discussions avec des personnes qualifiées sur le sida afin d'en confirmer la validité. De plus, une entrevue a fait l'objet d'une analyse par une tierce personne, experte dans l'analyse de contenu. Les résultats de cette analyse, reproduisant la deuxième étape, ont ensuite été confrontés à ceux des auteurs. La discussion s'est achevée par un accord commun sur les catégories, les sous-catégories et les concepts contenus dans le *verbatim*.

Limites méthodologiques

Cette étude est sélective et non exhaustive. Comme l'échantillon n'a pas été construit selon les principes statistiques aléatoires permettant une généralisation, les résultats ne peuvent être considérés représentatifs de la population homosexuelle québécoise de la génération des 30 ans vivant avec le sida. Cependant, ce qui peut avoir été perdu au en représentativité a probablement permis d'approfondir la signification des événements pour des sujets faisant partie d'une population aussi ciblée que celle-ci.

Un bref portrait des sujets

Des prénoms fictifs—ou la première lettre de ces derniers—ont été utilisés pour identifier les citations *verbatim* de cet article. L'âge moyen des hommes retenus pour cette étude est de 34,5 ans (28 à 41 ans). Trois d'entre eux possèdent une scolarité de niveau secondaire, trois autres de niveau collégial; un a complété un baccalauréat et un autre, un doctorat. Quatre des huit hommes retirent une assurance salaire et un seul, une assurance privée. Deux vivent de l'aide sociale et le dernier vit de ses propres économies.

Au moment de l'entrevue, la période sur laquelle s'échelonnait la connaissance de la séropositivité se situait entre quatre mois et neuf ans; celle de

la confirmation du diagnostic du sida entre quatre mois et trois ans. Deux de ces huit hommes offraient bénévolement un soutien psychologique à leurs camarades aussi atteints du sida.

Le sida comme maladie

Pour les participants à cette étude, à l'exception d'un seul, le sida est une maladie. Cette maladie, occasionnée par le virus de l'immunodéficience humaine (VIH), est conçue comme un processus morbide. Transitoire et intermittent, ce processus devient mortel au terme de son évolution par le biais d'une maladie opportuniste qui diffère en fonction de chaque personne (A,B,C,D,G,H).

François est la seule personne interviewée qui établit une nette différence entre le fait d'être atteint d'un virus et être atteint d'une maladie. Selon lui, les deux situations sont totalement différentes : on peut mourir d'une maladie mais pas du sida. Les effets d'une maladie sont visibles de l'extérieur—les autres peuvent dire «Voici une personne malade!»—alors qu'ils peuvent être inapparents dans le cas du sida. D'ailleurs, c'est pour cette raison qu'il serait difficile d'en limiter la propagation : l'invisibilité du virus jouerait contre la personne atteinte en lui permettant d'en ignorer pratiquement la présence. Pour Étienne, le sida est plutôt en compétition avec sa maladie opportuniste, une mucobactérie. Selon lui, le sida risque de mourir de faim. En effet, pendant que le sida s'affaire à gruger les T4 de son organisme même quand leur niveau est descendu de façon dramatique, la mucobactérie continue de travailler vaillamment de son côté. Celle-ci aurait donc de fortes chances de gagner la course et d'emporter Étienne dans la mort bien avant le sida.

Le sida existe sous deux formes dans les représentations des participants à cette étude : comme objet extérieur, il se manifeste par des symptômes physiques; comme objet intérieur, il gruge l'organisme. Le sida est une maladie qui tantôt profite des faiblesses biophysiologiques et tantôt s'attaque aux forces corporelles. Ainsi, un virus combattu normalement par une personne saine peut être mortel pour la personne atteinte du sida. Par exemple, une personne qui se connaît une fragilité à la gorge craindra que le virus du sida ne s'en prenne à ses poumons et l'emporte par une pneumonie. Pour une autre, le sida s'en prend àson cerveau, cette arme qu'il possédait pour lutter dans la vie. Ainsi, Denis soutient qu'il risque de perdre ses facultés intellectuelles et craint que l'évolution de la maladie l'entraîne dans la démence.

Toutefois, le sida tire toujours avantage des faiblesses psychologiques de l'être humain. Le sida est, pour Alain, une «bibite» qui reste cachée tant et aussi longtemps que son hôte la nourrit. Cet «acte de nourrir» est interrompu, dans ses représentations, lorsque la personne en vient à oublier la

maladie parce qu'elle se laisse gagner par des inquiétudes d'un autre ordre. Pour rester calme, le virus demande que jamais on n'ignore sa présence au profit de ses occupations usuelles. Satisfait de cette reconnaissance, le virus est rassasié et ne s'occupe pas de sa victime. Cependant, il demeure vigilant et, au moindre soubresaut d'inattention, reprend le dessus et se manifeste à nouveau.

Mal invisible, le sida sommeille à l'intérieur des personnes atteintes (E,F), mais une fois éveillé, il peut emporter son hôte dans la mort. Cet éveil est retardé ou précipité selon le mode de vie adopté, et c'est en prenant conscience de ce dernier que l'on pourra influer sur l'évolution de la maladie (A,B,C,F,H).

Le mode de vie, déclencheur, facilitateur et générateur de maladie

Dans les représentations de la santé et de la maladie (Herzlich, 1969), le mode de vie exerce une influence négative sur la santé et s'attaque aux endroits de moindre résistance. Il entraîne la personne vers un état intermédiaire, situé entre la santé et la maladie, où il y a diminution de la résistance et acquisition d'une plus grande vulnérabilité à la maladie.

Il en est ainsi de la séropositivité qui est la porte d'entrée du sida. Elle est vécue comme étape intermédiaire entre la santé et la maladie. Parfois équivalente au sida en raison de l'angoisse qu'elle éveille, elle en diffère parce qu'elle n'impose aucune limitation, permet de voir la vie comme avant la maladie et n'a pas son caractère inéluctablement fatal (B,C,E,F,G,H).

La personne atteinte du sida voit l'affaiblissement de son système comme étant sa seule responsabilité. Même si la constitution physique n'a pas résisté au virus, le tempérament permet de vivre avec la maladie, de ne pas se laisser déprimer et de mener la lutte jusqu'au bout sans mettre fin à ses jours. Il faut écouter son corps et ses états d'âme, bien s'alimenter, se reposer et se divertir afin de rester calme, détendu et maître des situations. Il faut exprimer sa colère, parler, ventiler ses émotions, cesser de tout garder pour soi. Ceci afin de se libérer des pressions qui stimulent le virus, qui lui permettent de prendre du terrain et qui empêchent de le combattre parce que l'on concentre son énergie sur autre chose. S'inquiéter pour des peccadilles ou des éléments non essentiels ne fait que disperser et diminuer l'énergie qui servirait autrement à combattre la maladie. Aussi, dès que l'on note un affaiblissement dans son système, il faut s'en occuper. Cela exige parfois une brève hospitalisation.

Les hommes interviewés dans cette étude ont donc une représentation correspondant au cadre de Herzlich (1969) dans lequel le mode de vie, vu de façon générale, joue trois rôles : ceux d'agent déclencheur, de facilitateur et de générateur de la maladie. Comme agent déclencheur, le mode de vie a permis l'agression d'un agent pathogène : le virus de l'immunodéficience humaine

(VIH). En tant qu'agent facilitateur, le mode de vie a affaibli le système immunitaire de la personne. Comme agent générateur, le mode de vie entraîne la personne vers des étapes plus avancées de la maladie. Toutefois, les hommes interrogés assument l'entière responsabilité de leur mode de vie homosexuel, plutôt que de le subir comme dans les représentations de la maladie telles qu'énoncées par Herzlich (1969).

La santé, effort d'aménagement du mode de vie nocif

Chez cinq des huit personnes interviewées, la santé prend la forme de la santé-équilibre telle que décrite par Herzlich (1969). La santé-équilibre est un état physique et psychologique immédiat qui implique un certain type de relation avec son milieu, relation où liberté et autonomie se confondent (A,D,F,H). La santé-équilibre permet à la personne de maintenir son autonomie face à ses occupations quotidiennes et à ses projets (A,F). Pour l'atteindre, la personne doit respecter une certaine hygiène de vie—s'alimenter convenablement, prendre suffisamment de repos, faire de l'exercice physique régulièrement, éviter le stress et conserver une attitude positive (B,C,F). Pour la maintenir, il faut apprendre à se contenter de projets à court terme (A,C,H). La santé-équilibre n'exclut pas la maladie; c'est d'ailleurs en équilibrant sa vie que l'on vivra plus longtemps en santé dans la maladie (A,B,C,F,H).

De multiples façons, la maladie amène les individus à un changement de leurs représentations de la santé. Denis décrit sa représentation de la santé d'avant la maladie en tant que fond de santé. Sa résistance et sa robustesse physiques constituaient un acquis, une règle, une norme. Il était né en santé et croyait la posséder jusqu'à sa mort. La maladie lui a fait prendre conscience de l'idéal qui entoure ce fond de santé : la santé n'est jamais acquise, c'est une expérience immédiate qui doit être renégociée constamment. Pour Étienne, on ne prend conscience de la santé qu'après l'avoir perdue. C'est la santé-vide à laquelle on aurait dû auparavant porter attention.

Toutefois, pour Georges, le concept de santé est un non-sens. Ne faisant aucune référence à la santé-vide, il explique que le fond de santé est pour lui une aberration totale et que la santé-équilibre est une absurdité forgée de toutes pièces par la société afin d'exploiter les besoins de l'individu, puisque les normes qui la définissent changent continuellement.

«On écoute les émissions, et je me demande s'il y a des gens qui sont en santé. Il y a toujours quelqu'un qui a une maladie ou qui a toujours quelque chose. La personne qui est en parfaite santé, je me demande si maintenant elle existe. (...) Ce qui, il y a 40 ans, n'était pas une maladie est maintenant une maladie. Vous êtes gros, c'est une maladie. Vous êtes trop mince, c'est une maladie. Vous êtes trop

pâle de figure, c'est une maladie. On dirait maintenant qu'il n'y a plus personne en parfaite santé.»

«Je pense que le plus bel exemple que l'on a de la santé, c'est—il y a 20-25 ans—on nous a fait quitter le beurre. On nous a dit : "Prenez de la margarine". Fantastique! Plus de gras, etc. Il y a un an, la même personne qui a chanté sur tous les toits de lâcher le beurre et de prendre la margarine revient et dit : "Ben, j'ai fait une erreur, c'est pas bon la margarine pour vous-autres." La même personne! Maudite innocente! On a changé toute une génération—à peu près 20 ans—on est tous passés à la margarine et là on nous dit : "Revenez donc au beurre".»

Pour les huit personnes, la santé avant le sida était vue en opposition à la maladie. La santé signifiait liberté, absence de contraintes, autonomie, alors que la maladie voulait dire dépendance, présence de contraintes, limitations, perte d'autonomie. La maladie leur a appris que la santé est une expérience autonome et immédiate qui peut coexister avec la maladie (A,B,C,D,F,H). C'est une présence dont on prend pleinement conscience après la maladie (B,D,E,F), qui permet d'agir (E) et qu'il faut préserver en adoptant certains comportements. C'est la santé-équilibre.

La maladie comme mode de vie

La maladie-destructrice

La maladie est vue comme destructrice par les personnes qui étaient actives avant la maladie (Herzlich, 1969). Par la faiblesse biophysiologique et l'incertitude face aux états corporels qu'elle engendre, la maladie-destructrice exige l'adaptation du mode de vie à l'état de santé. La personne est forcée de réduire ses heures de travail, puis de démissionner. Finalement contrainte à l'inactivité, la personne doit assumer la perte de sa fonction sociale et de ses rôles, l'abolition de ses projets de carrière et l'anticipation ou la venue de problèmes financiers.

Le mauvais pronostic de la maladie a aussi des implications sociales fâcheuses pour une jeune personne atteinte d'une maladie mortelle. Par exemple, Denis souligne l'impossibilité de pouvoir contracter une assurance, ce qui engendre chez lui la crainte de dépendre des secours publics, situation qui est, selon lui, pire que la mort.

«Oui, je ne me ferais pas mourir à travailler même si je ne suis pas en forme si je me faisais dire dans six mois, tu vas avoir levé les pattes. C'est pas si pire, tu sais. (...) Mais là, on ne peut pas planifier, on ne peut pas savoir. Il faut se dire, bon on continue parce que... J'ai plus peur du bien-être social que de la mort, en tout cas. C'est ça qui attend tous ceux qui ont le sida... À terme. Ça c'est accablant, ça.»

En même temps que la maladie-destructrice abolit les liens avec les autres, s'installe une perte d'autonomie graduelle qui établit la crainte d'être dépendant d'autrui. Le fait d'être en âge d'aider les autres—plutôt que de se faire aider—alimente la représentation de la maladie-destructrice. Pour François et Denis, cette situation humiliante est plus difficile à accepter que l'idée de la mort.

«ÇA C'EST DUR! Parce que je suis un gars qui est assez jeune, qui est prêt à aider d'autres gens qui sont en perte d'autonomie, mais moi, me faire aider quand... J'ai été une fois en perte d'autonomie, ça a été dur, j'en pleurais! C'était l'humiliation, je m'excuse. Alors avec le sida, il y a une affaire. J'ai pas peur de mourir, je l'ai bien accepté. Quand ça va venir le temps, je vais dire oui. J'ai même trouvé une raison pour mourir. (...) Ce dont j'ai peur, c'est de perdre mon autonomie. À 33 ans, je ne me vois pas porter des couches. C'est dur d'accepter que quelqu'un met un pot en-dessous de toi.»

La perte de sa fonction sociale et de ses rôles engendre un manque de contacts avec les autres qui vient accroître l'isolement provoqué par la perte de parents et d'amis. Certains se sont éloignés après la révélation de l'homosexualité et du sida. D'autres ont été mis à distance parce qu'ils entretiennent des sentiments de pitié qui ne sont ni constructifs, ni aidants.

Les changements dans les habitudes et les comportements sexuels de l'homme homosexuel atteint du sida alimentent ce manque de contact avec les autres. En effet, cet homme se retrouve avec les mêmes besoins, les mêmes désirs sexuels qu'avant la maladie, mais il n'a plus la même énergie physique, la même force pour y répondre. De plus, la révélation de sa séropositivité éloigne les partenaires sexuels potentiels.

Par la prise de médicaments et de traitements ainsi que par la participation à des protocoles de recherche, la maladie implique l'intégration d'un nouveau mode de vie (A,B,D,E,F,G) et la prise de conscience de l'impossibilité d'une guérison complète. Seule une période de latence comparable à une période de rémission est envisageable.

Cette prise de conscience confronte la personne à sa condition humaine : la vie est éphémère. Parce que ses jours sont comptés, Étienne voit l'anéantissement de son monde et soutient que cette situation a changé sa représentation de la vie. L'absence de perspectives et l'idée de la mort sont pour Denis l'équivalent de la mort elle-même. Cette vision est d'ailleurs partagée par d'autres personnes qui se laissent aller dans la consommation de drogue et d'alcool ou choisissent carrément de mettre fin à leurs jours. Ce laisser-aller, cet abandon, cette passivité est vue par les personnes atteintes qui continuent

de lutter comme «l'entraînement dans un déclin». La personne qui se laisse emporter par ce déclin est vue comme lasse et manquant de force de caractère. On dit «qu'elle tombe, qu'elle descend».

Faisant passer la personne de l'activité à l'inactivité, la maladie-destructrice l'entraîne vers une rupture biographique : il y a l'avant et l'après. Rupture des comportements quotidiens habituels, rupture dans sa vision de soi en rapport avec les autres, et mobilisation de nouvelles ressources cognitives et matérielles pour composer avec la situation récente (Carricaburu et Pierret, 1992).

Toutefois, même si l'issue de la maladie-destructrice est la mort (Herzlich, 1969), il semble que cette dernière puisse être retardée selon la façon dont la personne prend soin d'elle-même en vivant la santé-équilibre.

La maladie-métier

La représentation qui se superpose à celle de la maladie-destructrice chez les sujets interrogés (A,B,C,E,F,G) rejoint celle de la maladie-métier décrite par Herzlich (1969). La personne qui vit la maladie-métier accepte sa maladie et exerce un pouvoir sur celle-ci (Herzlich, 1969). Chez les hommes interviewés, ce pouvoir s'exerce en faisant face à la réalité. Cette confrontation comprend des éléments d'apprentissage et se traduit par l'adoption d'une nouvelle représentation de la maladie, qui devient un dernier défi à relever.

Malgré des états psychologiques qui varient de la crainte à l'acceptation, la personne fait de la maladie «une réalité» à laquelle dorénavant elle ne peut plus se soustraire. Alain ne veut pas perdre inutilement d'énergie à tenter de la remplacer par une autre réalité. Faire face à la réalité veut dire ventiler ses émotions, ses sentiments, ses états intérieurs et non essayer de les ignorer. C'est de cette façon qu'il sera possible de supporter la maladie, d'apprendre à vivre avec et de s'y adapter.

Alain l'exprime en ces termes :

«C'est quand je ne suis pas calme que ça a un effet... en tous cas... je sens que je stimule le virus, que je lui donne du terrain, tu sais... Que JE NE ME BATS PAS, parce que je mets de l'énergie sur autre chose.»

Toutefois, la société n'aide pas à accepter cette réalité; au contraire, elle oblige presque à la fuir. Et cela est absurde (A,G)! Écoutons les propos d'Alain:

«Ah oui, pour ma soeur, je n'ai pas de problèmes. Elle, par exemple, tout ce qu'elle me répond quand je parle de mort,... C'est que je peux mourir d'un accident d'auto. Je peux mourir d'un accident d'auto!

Comme si je pouvais envisager de mourir dans un accident d'auto! (...) Mais c'est pas ça. Tout le monde, on peut mourir d'un accident d'auto. Ça ne nous bouleverse pas. Quand la journée est finie, on se dit : "Bon j'en ai encore une à mon crédit, ça s'est bien passé. J'ai évité un accident d'auto". On ne se dit pas ça quand on est en santé, mais quand on est malade, on se dit : "La maladie, je l'ai encore surmontée une journée". C'est avec ça que je vis, je ne vis pas avec l'idée de la mort. Je... vis avec l'idée... c'est pas un accident d'auto qui va me faire mourir, je sais que je vais mourir du sida... Puis y a pas de statistique qui va prouver le contraire. Les statistiques devraient être de mon bord certain là-dessus. L'accident d'auto, pour moi, c'est complètement une absurdité.»

Pour cinq des sujets (A,B,C,F,G), il ne faut compter sur personne. La société est trop lente à changer ses représentations. Il faut s'aider soi-même, et c'est la seule façon qui permette de vivre avec le sida. Il faut changer sa propre représentation de condamné à mort, de victime. Il faut assumer sa responsabilité face à sa condition et y voir une occasion de croissance, d'épanouissement personnel.

Voici le point de vue de François :

«Surtout, je ne demande plus rien. Si je veux quelque chose, je dois aller le chercher. Finalement, on peut vivre avec le sida! Mon but, c'est d'envoyer le message au monde. De faire comprendre que l'on est plus des condamnés à mort. Je m'étais promis que je ne serais pas une victime du sida. (...) C'est facile jouer la victime : "Ah! Ce n'est pas de ma faute!" Je veux le vivre et je suis chanceux pour ça.»

C'est cette attitude qui permettra de voir la maladie comme source d'apprentissage : apprentissage de soi, des autres, de son environnement. Pour quatre des hommes participant à cette étude (A,B,C,F), la lutte contre la maladie est un combat qui s'apprend. François l'énonce comme suit :

«Tu sais, j'aurais pu continuer à faire à croire que j'avais rien. Je me promenais dans le passage, puis je disais aux gens: "Je suis séropositif". J'apprenais à le dire. J'apprenais à vivre avec la maladie.»

Cet apprentissage se fait par le biais d'un processus évolutif, par essais et erreurs. Il nécessite d'abord un état d'ouverture qui s'atteint en «laissant tomber tous les autres petits problèmes de la vie quotidienne», afin de concentrer son énergie pour s'informer et se familiariser avec ce nouvel état, cette nouvelle façon d'être (A,C). Puis, dans une étape ultime, cet apprentissage conduit à l'apprivoisement de la maladie.

Ces étapes visent à préserver l'intégrité biophysiologique et psychologi-que des personnes qui vivent avec la maladie. Les facteurs psychologiques sont de première importance pour passer de l'étape de maladie-destructrice à celle de maladie-métier et continuer la lutte à la maladie. Pour Bruno, qui n'a pas de famille, sa force réside dans le lien qu'il entretient avec son réseau de per-sonnes significatives (compagnon de vie, amis).

Toutefois, ce soutien ne se retrouve pas toujours auprès de personnes connues. Les réactions négatives de l'entourage font dire à Claude qu'il est parfois préférable de vivre l'isolement à fond et de laisser son réseau actuel d'amis s'anéantir; puis, de recommencer à se construire «une nouvelle gang, un nouveau monde qui accepte ça sans crainte, sans problème».

Chaque nouveau jour qu'il voit naître est pour l'homme atteint du sida une victoire sur la maladie. Ainsi, à travers les nombreux deuils qu'il a à vivre, il apprend à apprécier au jour le jour chaque manifestation de santé—comme de pouvoir à nouveau se servir de ses jambes—même s'il considère payer cher «ces moments de santé» qui lui sont accordés.

Il n'y a pas, chez les hommes interrogés, espoir de guérison comme dans la maladie-métier décrite par Herzlich (1969). Toutefois, on espère une évolution lente de la maladie. L'idée de la mort peut même être admise. On peut s'y préparer par différentes démarches. François a réussi à accepter la maladie et même la mort en se donnant une mission à accomplir une fois que cette dernière sera venue le chercher.

> «J'ai pas peur de mourir, je l'ai bien accepté. Quand ça va venir le temps, je vais dire oui. J'ai même trouvé une raison pour mourir... J'ai deux petites nièces puis... l'enfant de mon meilleur ami... J'ai décidé que quand, moi, je vais mourir, je vais devenir leur ange gardien. C'est peut-être juste une excuse, mais ça va m'aider quand ça va venir le temps de partir. J'ai un job à faire.»

La préparation à la mort est un appel criant à l'amour et au *caring* profes-sionnel, cette façon d'être et d'agir qui s'inscrit dans une relation transperson-nelle, celle de l'infirmière qui cherche à mobiliser le potentiel de la personne vivant avec une maladie (Watson, 1985). La vision idéalisée de sa propre mort est, pour Alain, sublimement transposée dans l'image de son chat qu'il a fait euthanasier. Il souhaiterait que son ami lui manifeste son amour en s'occu-pant de lui et en l'accompagnant dans ses derniers moments de vie. Mais comme il n'en est pas ainsi, il s'occupe lui-même de trouver un endroit où il recevra les soins et l'accompagnement nécessaires. Il aimerait que des soins professionnels lui soient prodigués, comme ceux du vétérinaire qui ont favorisé une mort douce et sereine pour son chat.

«J'ai donné mon nom à quatre places, là... Le soir j'ai annoncé ça à mon chum... plus j'y parlais, plus je me suis dit "Ben y va dire non". Il va dire "Tu n'iras pas là. Tu n'iras pas dans une maison avec des étrangers. Je suis là moi. Je suis ton chum. Ça fait 11 ans que l'on est ensemble, bla-bla-bla..." Il n'a rien dit. Ça fait que là, hier, après que le chat ait été euthanasié, je suis revenu à pied. (Hausse la voix) POUR VOUS DIRE COMMENT J'AI PLEURÉ QUAND J'AI FAIT EUTHANASIÉ MON CHAT, le vétérinaire m'a rien chargé. J'ai assez pleuré là, que là j'ai dit... là j'ai sorti l'argent... parce qu'au téléphone, je m'étais informé combien..., il a dit "Non... laisse faire". J'ai dit : "Voyons, vous êtes un professionnel, ça été bien fait, je suis content que ça se soit passé comme ça". Je l'ai eu dans mes bras, j'ai eu l'impression de l'endormir, de l'aider à quelque part là.»

Même si on peut se faire à l'idée de la mort, on ne peut jamais se faire àcelle de la perte d'autonomie (D,F). Malgré que la maladie puisse être apprivoisée et devenir plus acceptable, le spectre de la perte d'autonomie, de la dépendance envers autrui, rôde toujours et en entretient l'aspect destructeur.

Pour cinq sujets (A,C,E,F,G), il faut plutôt lutter contre la dépendance àl'égard d'autrui. Il faut savoir prévoir et être en mesure de faire face au jour où il sera impossible de prendre soin de soi. Il faut prévoir de l'aide sous une forme ou une autre : par des services à domicile ou en allant les chercher à l'extérieur. Ou encore en réservant sa place dans un foyer.

La personne «prépare le terrain». Si elle devient dépendante, sa place est vraiment dans un foyer. Cette préparation est vue comme étant la responsabilité de la personne atteinte. Il ne faut pas remettre à plus tard, mais agir maintenant tandis qu'on peut encore le faire. La possibilité de faire des projets à long terme étant éteinte, il faut apprendre à vivre à court et moyen terme.

La lutte contre la maladie en suppose également la connaissance (Herzlich, 1969). D'ailleurs, pour Bruno, on en vient à la maladie-métier après avoir réalisé l'ignorance de la médecine entourant le traitement du sida. On essaie des médicaments qui parfois détériorent l'état de santé. C'est pourquoi il vaut mieux prendre soi-même son traitement en main et s'informer sur les traitements de pointe et leurs effets secondaires, et décider pour soi de les suivre ou non.

Pour ce faire, la personne guidée par la représentation de la maladie-métier suit de près les dernières percées scientifiques. Cette conduite donne à la personne malade un pouvoir sur sa maladie, pouvoir qui lui permettrait peut-être même d'éviter la mort si les découvertes scientifiques se faisaient plus rapidement. Cependant, on a parfois besoin d'une pause pour refaire ses

forces, ses énergies, car la maladie-métier demande un effort soutenu. Alain, qui est hospitalisé depuis quelques semaines pour traitements, voit son congé de l'hôpital comme «une libération conditionnelle». Bruno, qui s'efforce de conserver une attitude positive, aimerait prendre congé de sa maladie-métier pour refaire le plein d'énergies.

> «Tu dis: "Bon, c'est bien beau avoir le moral, là". De dire *Let's go*, j'aime bien la vie, là". Mais il y a des soirs-là où je veux dire, tu fais PFUT! Je suis tanné moi-là, je prendrais un break tu sais.»

La maladie-métier est vécue par l'homme homosexuel atteint du sida sous forme d'étapes, dans un processus évolutif. Après avoir atteint un état d'ouverture, il entame un processus d'apprentissage qui le conduit à l'adaptation à un nouveau mode de vie dans lequel il intègre les limitations imposées par la maladie, ses propres compensations et ses nouveaux intérêts, pour enfin s'ouvrir à un apprivoisement de la maladie. À travers ces étapes, il apprend à lutter et à devenir plus fort. Cette force lui permet d'atteindre la santé-équilibre et de s'y maintenir autant que possible. Elle lui permet aussi de préparer sa mort.

Pour Claude,

> «C'est peut-être le dernier grand défi que j'ai à vivre avant de mourir. Puis, je ne m'attends pas d'y mettre fin, à moins qu'il y ait vraiment quelque chose qui tourne mal. J'ai l'intention de vivre jusqu'au bout, de combattre jusqu'au bout.»

Cependant, franchir les étapes de la maladie-métier est indissociable de l'appui du réseau social, qui est essentiel pour qu'une réorganisation de l'identité du sujet s'amorce et lui permette le maintien des sentiments d'appartenance sociale et de compréhension de ses pairs.

Comme dans le cadre de Herzlich (1969), la lutte contre la maladie s'apprend. Toutefois, à son opposé, l'issue de la maladie-métier ne se situe pas dans la guérison, mais plutôt dans le maintien d'une qualité de vie en attendant la mort qui a été préalablement acceptée. Ceci s'explique facilement par le fait que le sida est vu comme une maladie inéluctablement mortelle.

De la maladie-libératrice à la maladie-croissance

Des auteurs ont relevé la présence d'un processus évolutif chez l'homme atteint du sida, à travers lequel la vision de la maladie se transforme (Lamendola et Newman, 1994; Nokes, 1992). Après avoir assumé de nombreuses pertes et intégré de multiples deuils, les personnes s'ouvrent à une nouvelle conscience de la vie.

On retrouve chez les hommes interrogés une représentation de la maladie qui ne se rapproche que d'une seule des deux conceptions de la maladie-libératrice telle que conçue par Herzlich (1969). En effet, dans le cadre théorique des représentations de la santé et de la maladie (Herzlich, 1969), l'allégement des charges et l'abandon des responsabilités peut entraîner une rupture bénéfique du quotidien et des obligations sociales. Comme signalé dans la section traitant de la maladie-destructrice, aucun des hommes faisant partie de l'étude ne voit l'abandon de ses responsabilités sociales comme une libération. Au contraire, cette conséquence de la maladie est vue comme totalement destructrice.

Toutefois, les représentations des hommes interrogés se rapprochent davantage de celle de la maladie-libératrice de Herzlich (1969) qui englobe la maladie grave, la mort, la douleur dans lesquelles les significations sont plus intenses. Aussi, pour mieux différencier les deux conceptions de la maladie-libératrice telles qu'énoncées par Herzlich (1969), il serait préférable de renommer maladie-croissance, plutôt que maladie-libératrice, la représentation de la maladie qui entraîne un changement de valeurs, la personne se retrouvant devant elle-même, face à sa solitude, à sa vérité.

Cependant, l'évasion dans la maladie ne se fait pas, comme dans le cadre de Herzlich (1969), avec l'accord de la société. Chez les hommes interviewés dans cette étude, l'évasion dans la maladie se fait dans l'affirmation de la double déviance sociale, entraînée par l'homosexualité et le sida.

La modification des valeurs se retrouve chez trois des huit sujets interviewés (A,C,F). François raconte :

«Finalement, moi, je suis heureux d'avoir le sida parce que ça m'a éveillé aux valeurs de la vie. (...) je n'appréciais pas la vie pour ce qu'elle était. Je la prenais pour acquise. Si je suis rendu là, c'est parce que j'ai le sida.»

Alain est en quête de sa propre vérité :

«J'ai même fait des démarches—hier, avec la religieuse, mais la religion n'a rien à faire là-dedans—pour aller en cure de silence, pour dormir, à Oka—ou je ne sais pas où, à Saint-Benoît-du-Lac—pour me retrouver avec moi-même parce que (...).»

La personne vit une transformation, «un enrichissement». L'expérience de la maladie peut avoir «une valeur formatrice, liée à la douleur, à la menace de la mort» (Herzlich, 1969, p. 154). Elle suscite réflexion, lucidité, connaissance de soi, ouverture à autrui et même... atteinte du bonheur.

Selon Alain :

«Dans la maladie, on apprend beaucoup, c'est très enrichissant. J'ai appris beaucoup de choses. Je pensais que j'aurais appris sur la mort. Sur la mort, je n'ai rien appris encore. J'ai appris des affaires sur moi, sur les ressources que l'on a... intérieures, pour passer sur des affaires. J'ai appris sur mon conjoint, j'ai appris sur ma famille, j'ai appris sur mes amis, cela a fait beaucoup.»

Pour François :

«Ces derniers deux ans, je me suis dit : "Oh! Il ne m'en reste pas gros. C'est ma dernière chance, moi là, là. On ne me redonnera plus d'autres chances d'être heureux." Là, c'est ma dernière chance d'être heureux. C'est pour ça que je suis heureux maintenant. Je ne souhaite plus des millions. Ce n'est pas ça qui va me rendre heureux. Je souhaite que ça continue comme ça. C'est ça mon souhait à tous les jours.»

Selon les hommes interviewés, pour passer de la maladie-métier à la maladie-croissance, il faut «avoir accepté la mort». Cette acceptation permet d'atteindre «une tranquillité», «une paix intérieure» telle qu'elle sera vécue quand le combat avec la maladie sera terminé. La maladie-croissance devenant, dans les représentations, un avant-goût de ce que sera la vie... après la maladie.

Ainsi, pour Claude :

«C'est comme moins difficile aussi à partir du moment où tu arrives à accepter que tu vas mourir... Ça peut être aujourd'hui. Ça peut être sur la rue... Puis à partir du moment où tu l'acceptes de cette façon là, ça en devient même une paix intérieure... plus grande. Bon, à un moment où à un autre, tu vas partir. Que ce soit avec une maladie grave ou en me faisant écraser en traversant la rue... Je vais partir. Mais en l'acceptant et en le vivant comme ça à tous les jours, ça aide. Ça apaise un peu la crainte de partir. On apprends à vivre... peut-être déjà un petit peu l'autre côté, en disant : "Bon, ça va être la paix. On va avoir la tranquillité. Puis... le combat va être fini."»

De destructrice qu'elle était à ses débuts, la maladie a éveillé une force intérieure qui a entraîné un sentiment de réalisation, d'accomplissement de soi. Enfin, la maladie est devenue un outil de découverte de sa vraie personnalité. Les hommes interrogés soutiennent que cette découverte n'aurait pas eu lieu si ce n'eût été du sida.

Conclusion

Jamais conceptualisé en termes biophysiologiques mais plutôt en termes relationnels, le sida est, pour les participants à cette étude, relié au mode de vie, agent déclencheur, facilitateur ou générateur de la maladie. Toutefois, dans leurs représentations, les hommes interrogés assument l'entière responsabilité de leur mode de vie homosexuel, plutôt que de le subir comme dans les représentations de la santé et de la maladie telles que conceptualisées par Herzlich (1969).

Attaquant à la fois leur corps et leur esprit, le sida est vu tantôt comme maladie-destructrice, tantôt comme maladie-métier ou comme maladie-croissance. Ces trois images de la maladie coexistent dans un processus évolutif. Et la maladie n'exclut pas la santé.

En effet, le sida entraîne un changement, par étapes, des représentations des concepts de santé et de maladie. Conçue comme l'opposé total de la maladie avant l'infection par le VIH/sida, la santé devient, après l'atteinte de l'organisme par la maladie, une expérience autonome et immédiate qui coexiste avec la maladie. La santé-équilibre procure un bien-être corporel, psychologique et fonctionnel.

Le sida, comme maladie-destructrice, est une maladie sournoise, grave, mortelle, contagieuse, stigmatisante, à caractère épidémique, qui fait vivre une rupture biographique et la crainte de la dépendance envers autrui. Comme maladie-métier, le sida est un combat qui s'apprend. Il rejoint les notions d'adaptation, d'apprivoisement, d'ajustement à la maladie et d'acceptation de la mort. Il entraîne une lutte contre la dépendance et traduit un appel criant à l'amour et au *caring* professionnel. Puisqu'il s'agit d'une maladie mortelle, l'issue de la maladie-métier est le maintien d'une qualité de vie, et non pas la guérison.

Le sida, c'est aussi un outil de découverte de soi, d'ouverture aux autres, de révélation des vraies valeurs, entraînant un sentiment d'accomplissement personnel, de transformation, d'enrichissement, de paix intérieure. C'est la maladie-libératrice, telle que perçue chez les personnes atteintes d'une maladie grave et qui sont confrontées à la mort (Herzlich, 1969), qui pourrait plutôt être renommée «maladie-croissance» afin de mieux souligner les aspects de dépassement de soi, d'atteinte d'un autre niveau de conscience.

Cette étude révèle le lien indissociable entre la personne et son environnement et, l'importance de ce dernier dans la vision que la personne a du monde qui l'entoure et dans le sens qu'elle donne à sa vie. Le cadre des représentations sociales de la santé et de la maladie (Herzlich, 1969) constitue un moyen de connaissance et d'action nécessaire à l'infirmière pour préciser sa démarche d'accompagnement des personnes atteintes du sida.

La connaissance des représentations sociales, en rapport à la santé et à la maladie, livre aux infirmières un nouvel outil heuristique leur permettant, à la fois, de comprendre le processus évolutif que traverse l'homme atteint du sida et d'intégrer davantage dans leur pratique les valeurs congruentes au soin infirmier global *(caring)*.

Dans cette optique, la prise de conscience par l'infirmière de ses propres représentations de l'homosexualité et du sida lui permettra de modifier le filtre à la communication qui existerait et qui nuirait à l'établissement d'une relation thérapeutique. Reposant sur une façon d'être en relation absente de préjugés, cette relation thérapeutique favorise la mise en valeur de l'autre, lui permet d'utiliser son énergie et ses capacités pour interagir avec son milieu, développer son potentiel et s'actualiser. Situé dans le cadre de la santé et de la maladie, le soutien de l'infirmière aide l'homme atteint du sida à adopter des comportements et des habitudes de vie qui soient générateurs de santé-équilibre, même à travers la maladie. De plus, cet accompagnement donne accès à une meilleure qualité de vie. Et ultimement, à une mort douce et sereine.

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Remerciements

Data Sharing in Nursing Research: Advantages and Challenges

Carole A. Estabrooks and Donna M. Romyn

La documentation en sciences infirmières s'est peu attachée à divulguer l'information entre clini-ciens-chercheurs. Le présent article relève la pertinence pour les chercheurs en sciences infirmières de faire connaître l'information et examine le genre d'information qui peut être divul-gué. Les avantages, les inconvénients et les questions concernant le fait de faire circuler l'informa-tion sont abordés et des recommandations pour un plus grand partage de l'information entre les enquêteurs sont avancées. Les auteurs estiment qu'il est préférable de faire connaître les conclu-sions des recherches et que les chercheurs en sciences infirmières devraient viser à déposer dans des archives accessibles les résultats de projets de recherche en sciences infirmières financés par le public. Ils considèrent également que les chercheurs en sciences infirmières doivent intégrer des projets de partage des connaissances dans leurs programmes de recherche et demander les infra-structures nécessaires pour ce faire.

The sharing of data between investigators has received little attention in the nursing literature. Among other advantages, data sharing reinforces open scientific inquiry, encourages the develop-ment of multiple perspectives, and reduces respondent burden. However, ownership and control of the shared data, preservation of respondents' anonymity, and the costs of data sharing are among the issues that need to be addressed in agreements and contracts involving primary inves-tigators, secondary investigators, and data repositories. The original researcher must spend time and energy to make data sharing possible. It is only when such efforts are acknowledged and rewarded that data sharing is likely to become a norm in the nursing profession. The authors argue that research data should be shared and nurse researchers should seek to have data from all publicly funded projects deposited in accessible data repositories. Nurse researchers need to incorporate plans for data sharing into their research programs and press for the infrastructures required to enable data sharing.

Data sharing as a topic of interest to nurse researchers has received little attention in the literature, with only a handful of papers available (Aaronson, 1990; Gleit & Graham, 1989; Jacobson, Hamilton & Galloway, 1993; McArt & McDougal, 1985). On the simplest level, the term data sharing means the sharing of data between investigators, however it is a complex concept. In an analysis of the literature Hilgartner and Brandt-Rauf (1994) describe at least four perspectives from which data sharing has been examined: the ethics of data sharing and ownership, scientific findings as communal property, intel-lectual property rights, and university-industry relations (p. 356). In the nurs-ing literature, data sharing is generally addressed, if addressed at all, within the context of secondary analysis, which has also received scant attention. It has been suggested that this lack of attention to data sharing and secondary analysis reflects a norm within the profession in which greater value is assigned to primary data collection (Herron, 1989; McArt & McDougal, 1985; Thorne,

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1994). If this is indeed the case, it is not surprising that data sharing, on which secondary analyses are often predicated, has received little attention. We anticipate that in the future, secondary analysis will assume a higher profile in nursing research and that nursing will revise its norms and values to reflect the importance of both primary and secondary approaches to data analysis and the sharing of data between investigators.

Since the early 1960s, data sharing has been an issue in the social sciences (Hedrick, 1988) where there is a growing awareness of, and mandate for, the sharing of research data (Fienberg, Martin & Straf, 1985; Sieber, 1991b). In fact, some funding agencies such as the National Science Foundation (NSF) in the United States and the Social Sciences and Humanities Research Council (SSHRC) of Canada have established policies requiring investigators to deposit their data in a public archive within a designated time period after completion of their studies. Given the current social, political and economic climate, it is reasonable to expect that in the future, nurse researchers will also be required to make their databases broadly available to secondary investigators. Aaronson (1990) specifically addressed the need for data sharing and the development of a repository of nursing data. We contend that the data from all publicly funded nursing research projects should be in controlled and publicly accessible data repositories.

The purpose of the current paper is to explore the relevance of data sharing for nursing research and to examine courses of action that would facilitate data sharing within the discipline. More specifically, we discuss the kinds of data that ought to be shared and some of the advantages, issues, and challenges of data sharing. In the final section, we make recommendations to encourage more activity in this area. Without a clear understanding of the potential advantages and the issues related to data sharing, it is unlikely that nurse researchers will begin to integrate plans for it into their research programs or press for the infrastructure required to enable data sharing.

For the purposes of this paper, data sharing is broadly defined to include a broad range of sharing, from the willingness of a primary investigator to provide a copy of the data to another investigator, to the placement of data in formal repositories where they become part of the public domain. Although data sharing in its broadest conceptualization includes the sharing of institutional data such as those generated by health information systems and minimum data sets, the issues involved in sharing such data are somewhat different and have thus been excluded from our discussion. In addition, although the authors encourage the establishment and maintenance of data repositories for nursing research, we will not discuss their structures and functions here. For purposes of the current paper, the literature cited from January 1983 to December 1994 was reviewed using the CINHAL, SSCI and MEDLINE

bibliographic databases. Search terms included *data sharing, secondary data analysis, data repositories,* and *data archives.* In addition, the reference lists of each of the retrieved articles were manually searched to ensure that important materials were not missed.

What Data Ought to be Shared?

When considering the kinds of data which ought to be shared, most often researchers think of survey data. This is probably a result of the considerable work done in the area of data sharing in the social sciences where surveys are used extensively. We contend that it is counterproductive for nursing to limit itself to this narrow notion of what constitutes shareable data. Nurse researchers need to consider sharing a wide range of data including field notes, interview data, audio/video tapes, photographs, and research diaries. Technology is rapidly making it possible to efficiently create, store, and retrieve various other forms of data and to handle the large text-form data sets that often characterize qualitative research (White, 1991; Wolfe, Gephart & Johnson, 1993). While little has been written about the preservation and sharing of data generated from qualitative nursing research White (1991), for example, has outlined some of the issues inherent in sharing qualitative anthropological data. The qualitative data sets generated by nurse researchers offer a rich source of data which need to be considered in determining the kinds of data that ought to be shared within the discipline.

Advantages of Data Sharing

The advantages of secondary analysis and data sharing have been enumerated by several authors, mostly in the non-nursing literature (Aaronson, 1990; Abel & Sherman, 1991; Card & Peterson, 1991; Fienberg, 1994; Fienberg, Martin & Straf, 1985; Gleit & Graham, 1989; Hedrick, 1985, 1988; Jacobson, Hamilton & Galloway, 1993; Lobo, 1986; McArt & McDougal, 1985; Sieber, 1989, 1991a, 1991b). These ideas are succinctly and accurately summarized by Hedrick (1985, 1988). The current paper focuses on the advantages identified by Hedrick (1988) that have the most relevance for nursing research: reinforcement of open scientific inquiry; verification, refutation, or refinement of original results; exploration of new questions; development of multiple perspectives; reduction of respondent burden; and development of knowledge about research and analytic techniques.

Reinforcement of open scientific inquiry. It is generally accepted that open scientific inquiry is an ethos in nursing. A climate of openness enables science to be self-correcting and cumulative and to benefit from multiple perspectives (Sieber, 1991a). Within nursing, data sharing permits extension of the work of primary nurse investigators as other nurse researchers use the

available data in various ways in their projects. Data sharing allows gaps in theoretical knowledge, identified either by the primary or secondary investigator, to be addressed. It also affords opportunities for theory building and theory testing, which may not otherwise be available. However, in an environment where promotion, tenure, and publication are important motivating forces, nurse researchers may be reluctant, as are many social scientists (Ceci, 1988; Ceci & Walker, 1983; Sieber, 1991a), to share their data freely. Nevertheless, there is a growing recognition that individual research efforts are not as fruitful in developing nursing knowledge as the collaborative endeavours of several nurse researchers working in the same area of interest. The challenge for nursing is to demonstrate that such academic rewards as tenure and publication are better promoted through sharing rather than amassing and storing data.

Verification, refutation, or refinement of original results. In a climate of openness, data sharing enhances the honest reporting of findings. Scientific fraud has been rare in nursing research (Hawley & Jeffers, 1992). However, it is probably naive to think that the profession is not vulnerable to scientific misconduct similar to the recently reported misrepresentation of data in a breast cancer study or that described by Broad and Wade (1982) and addressed in recent issues of *Knowledge: Creation, Diffusion, Utilization* (LaFollet, 1992) and *Scholarly Publishing* (Carroll, Montagnes, & Shipton, 1993). Secondary analyses, which are made possible by data sharing, serve to improve the accuracy of findings, provide for the refinement and/or confirmation of results, and for the identification of problematic conclusions. Furthermore, different or additional findings may result when secondary investigators employ analytical and statistical techniques other than those used by or available to the original investigators.

Explorations of new questions. Data sharing allows questions to be posed and theories to be tested in new and different ways that otherwise would not be possible. As yet, nursing does not have a tradition of fully exploiting the data collected through research because of limitations in resources including time, money, personnel, expertise, and the constraints of individual research programs. This is particularly true of qualitative research, which often produces far more data than can be managed in any one study or by any one investigator. Furthermore, there may be several legitimate and supportable interpretations of the same textual data, which would be lost to the discipline if secondary analysis is not conducted by the primary investigator or another researcher. In both qualitative and quantitative analyses, nurse researchers need to debate the extent to which the assumptions underlying the secondary analysis must be consistent with those of the original study and the implications that inconsistencies may have for generating valid findings. Once the inherent scholarly, ethical, and technical issues related to data sharing have been reasonably addressed, it will likely be recognized that both qualitative

and quantitative data sets are appropriate for sharing, and that such sharing generates new and different theoretical directions.

Encouragement of multiple perspectives. Data sharing enables the exploration of concepts from new perspectives, raising different questions and using different methods. It allows an exchange of data with other disciplines and permits each to explore similar concepts from their own perspective. Further, data sharing facilitates interdisciplinary research endeavours when the various perspectives and methods of several disciplines are brought to bear upon the same concept. It allows researchers to aggregate findings, pursue different aspects of a particular question, and develop more complete theories.

Reduction of respondent burden. The cumulative demands of time and physical and emotional energy that nurse researchers create for respondents have not received much attention in the nursing literature. Respondent burden is of particular importance in cases where there are few respondents exhibiting a particular phenomenon or where the health of the individual is such that repeated data collection is not feasible or ethical. By sharing data, nurse researchers make available data regarding how people, and in particular people comprising vulnerable populations, experience and manage their health. As a result, respondent burden is reduced and rare data sets are more completely utilized.

A related advantage of data sharing not addressed by Hedrick (1988) but highlighted by many authors is the *economy of resources* that can be realized in terms of people, time, money, and other assets. With research funding sources increasingly under pressure to downsize, researchers are likely to have increasing difficulty obtaining funds for major projects. Funding agencies can be expected to demand more efficiency and accountability in the use of databases that are expensive to collect and often result in considerable respondent burden.

Development of knowledge about research and analytic techniques. Nursing students are frequently exposed to research methods and statistics as separate subjects. The use of actual data sets, made possible by the sharing of data, is an effective way to encourage the integration of theory and knowledge of research methods and statistics, and needs to be encouraged by nurse educators. The use of shared data sets enables graduate students to participate in the research process without having to engage in costly and time intensive data collection (Abel and Sherman, 1991; Gooding, 1988). While data sets from other disciplines may serve the necessary educational purposes, the use of data sets generated by nurse researchers in response to the kinds of questions that nurses ask will enable nursing graduate students to learn in the tradition of their discipline. Sieber and Trumbo (1991) suggest that one of the advantages of using a data set generated by someone other than the teacher of the particular research course is that it facilitates learning without the constraints

that might be imposed by the presence of the researcher, whose data are in all likelihood, imperfect in some way.

Issues and Challenges

Data sharing holds great promise for knowledge development within nursing. Despite this, numerous issues and challenges need to be addressed if nurse researchers are to be convinced of its merits and participate effectively in data sharing. Some of these include ownership and control of data, time frames for data sharing, costs, documentation, and ethical issues. As daunting as some of these may seem, they should not be deterrents to the sharing of nursing research data. Rather, they need to be explored so that thoughtful solutions can be formulated.

Ownership and control of data. Two common issues regarding data sharing are ownership and control of the original data set.[1] Resolution of these issues will vary depending upon the arrangements made for sharing. If the data are to be shared through a data repository, ownership and responsibility for maintenance and distribution of the data set generally rests with the repository. Unless specific limitations are established regarding who may access the data, the data become part of the public domain. If the data are to be shared on a more informal basis, such as between colleagues, the original investigator generally retains greater control and thus can determine who may access the data and for what purposes. This may include, but is not limited to, data obtained in participatory research with consumer groups. We recommend that in cases where data are to be shared in this way that an agreement or contract be established between the original and secondary investigators which clearly outlines the rights, responsibilities, and obligations of each. Such agreements should include, at minimum, a description of the data set and the supporting documentation, an estimation of the costs involved in the sharing of the data, and the responsibilities of each in covering such expenses. Further, it must be clearly established how appropriate reference citations and acknowledgements of the original researcher will be provided in subsequent publications and scholarly presentations.

Ownership and control of newly created data sets resulting from the combination of two or more previously existing data sets have not been clearly addressed in either the social sciences or nursing literature. Generally, if the original data sets were obtained from a data repository it would be

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1 Ownership, within the context of research data, may be more appropriately viewed as stewardship. Ownership connotes exclusive control over and use of data (a connotation that nursing may be reticent to adopt), whereas stewardship implies that the data are held in trust rather than owned.

appropriate for the secondary investigator to ask whether the new data set should be deposited within the repository. In cases where the data were obtained from one or more original investigators, we recommend that an explicit agreement be established prior to data sharing. It should address the secondary investigator's responsibilities related to sharing the new database and its supporting documentation, and the timing of such sharing.

Time frames for data sharing. Investigators unfamiliar with data sharing may question within what time period data sets should be made available to others. Such questions often reflect concerns regarding being preempted in publications and other scholarly endeavours (Ceci, 1988; Ceci & Walker, 1983; Sieber, 1991a). Funding agencies may specify the time frame for data sharing or, as in the case of SSHRC, they may provide general guidelines such as "within a reasonable time period." It is generally recommended that original investigators make their data sets available after the initial data analysis and preparation of major publications have been completed.

Costs. Issues related to the costs associated with data sharing may become contentious if agreements between investigators regarding who will assume responsibility for specific costs are not carefully crafted. In the social sciences, it is generally accepted that the secondary investigator ought to bear the costs of obtaining the data. This may include, but is not necessarily limited to, costs of copying the data set in a machine-readable format; duplication of questionnaires, code books and other relevant documentation; postage; and in the case of qualitative data, duplication of field notes, video or audio tapes, photographs, and other available data. Funding agencies such as NSF and SSHRC who require that original investigators make their data available to repositories, encourage investigators to include data sharing costs in their proposal budgets. While this practice is not yet prevalent in nursing, nurse researchers need to begin to identify such costs in proposal budgets. In this way funding agencies will be made more aware of the logistics and associated costs of data sharing.

Documentation. One of the challenges in planning for data sharing is the preparation of the supporting documentation which provides crucial information regarding the data set (David, 1991). It is the responsibility of the original investigator to ensure that the data set is accurate and that the supporting documentation is adequate to allow the secondary investigators to decide whether or not the data set is appropriate for their purposes and, if so, to utilize the data effectively and efficiently. Normally this documentation exists as some form of the codebook, providing a legend for the study. The provison of a detailed codebook reduces the time spent by the original investigator answering routine questions regarding the data sets. The codebook may include information regarding the theoretical and conceptual basis of the

study, underlying assumptions, sampling procedures, the original design for data collection and any deviations from that design. It should also include copies of instruments utilized, results of testing for reliability and validity, assumptions underlying particular questions or instruments, derived measures, and information regarding data transformations, aggregation procedures, and the creation of new variables. Decisions made regarding data coding and analysis also need to be recorded so that future investigators are not left to guess what was done and the original investigator is not left trying to recall such decisions some time later. In planning for the deposit of data in a repository, nurse researchers should ensure that they have met any additional requirements that data repositories may have.

If quantitative data sets are to be useful to other researchers they must be in a machine-readable format appropriate for use with one of the commonly available statistical packages. Similarly, qualitative data sets need to be compatible with software packages specifically developed for the analysis of qualitative data such as Ethnograph, NUDIST, and Hypertext (Richards & Richards, 1994; Tesch, 1990). Data should be stored on floppy diskettes, magnetic tape or optical disks, and subsequent researchers must ensure that they have appropriate and adequate computer resources to retrieve and analyze them. With advances in computer technology, data transfer is becoming, and will continue to become, less problematic for the secondary investigator.

Ethical issues. The ethics of secondary data analysis and the safeguarding of respondents' anonymity are issues that concern researchers in nursing and the social sciences (Baron, 1988; Ceci & Walker, 1983; McArt & McDougal, 1985). The current trend in nursing is to include provisions for secondary data analysis in consent forms which facilitates data sharing. However, data sharing is precluded if respondents' anonymity cannot be protected. While this is primarily the responsibility of the original investigator, data repositories also share some responsibility for ensuring that data sets accepted for deposit do not contain information which could be utilized to identify respondents. Of particular concern is the potential for cross-referencing when data sets are combined. For example, the identification of particular individuals may occur when some respondent characteristics are cross-referenced with specific geographical and occupational data. While ensuring anonymity may not be a problem when a data set involves a large survey sample, researchers may need to be more creative when the data set is comprised of a small sample and/or includes some forms of qualitative data sets. For example, in the case of qualitative data stored on video or audio tapes or in photographs, it may be necessary to employ electronic measures to disguise voices or facial features that identify the respondents. However, this may not be possible without destruction of the data. In such a situation, the original investigator must judge the appropriateness of sharing the data.

Recommendations

It is clear that data sharing, despite its challenges, has considerable potential for facilitating knowledge development in nursing. However, for this to occur nurse researchers must be convinced of its merits and be willing to support data sharing as a worthwhile endeavour. Toward this end, we make the following recommendations.

First, nurse researchers and scholars need to engage in ongoing debate regarding the advantages and disadvantages of data sharing to develop common understandings and guidelines. In particular, they must carefully consider the ethical issues that are likely embedded in the practice of data sharing. We need to establish guidelines that are appropriate to the assumptions underlying particular research traditions. We need to develop standards regarding the quality of data sets and the accompanying documentation which are to be shared. Input should be sought from such sources as nurse (and other) investigators, educators, professional associations, journal editors, consortia for data archiving, and funding agencies (Fienberg, Martin & Straf, 1985).

Second, in terms of professional rewards, criteria for promotion and tenure need to acknowledge not only primary research, but also the efforts required to prepare data sets for sharing, and the endeavours of secondary investigators. Secondary investigators need to consistently cite the original data set and, where appropriate, the data repository in which the data are located (Fienberg, Martin & Straf, 1985). It has been suggested that in the social sciences some journal editors have held a bias toward publishing primary as opposed to secondary research (Fienberg, Martin & Straf, 1985). Nursing has the opportunity to circumvent this concern if journal editors continue to ensure that sound research based on shared data is given equal opportunity for publication.

Third, nurse researchers need to plan for data sharing during the initial phases of proposal development and ensure that the supporting documentation is developed as the research progresses (Fienberg, Martin & Straf, 1985; Sieber, 1991b). Otherwise, important information pertinent to the study and subsequent analysis of the shared data may be lost to secondary investigators. One strategy for achieving this is to include a data archivist as an integral member of the research team from the beginning of the project. Funding agencies need to encourage data sharing by providing the resources required for the preparation of data, including the supporting documentation, for deposit in a data repository. In fact, Sieber (1991b) suggests that research proposals that include plans for data sharing should be given priority for funding. Funding also needs to be made available for the development and ongoing maintenance of data repositories. Nursing may not need to develop its own repositories but

could, as Aaronson (1990) suggests, establish specialty nursing archives within existing data repositories. In so doing, the costs of developing such an infra-structure would be reduced and the data made available not only to other nurse researchers, but to investigators from other disciplines as well.

Fourth, to facilitate the retrieval of shared data, nurse researchers need to work toward developing and maintaining a current directory of data sources that nurse researchers can access, similar to those developed by Jacobson, Hamilton and Galloway (1993), Kiecolt and Nathan (1985), McArt and McDougal (1985), and Saba, Oatway and Rieder (1989). However, unless the resources are available and a concerted effort is made to add new sources and ensure that the entries are correct, such directories will quickly become out-dated. To facilitate retrieval, a classification system that enables users to deter-mine the quality of the data set and accompanying documentation would be useful. Such a system was developed by the Inter-University Consortium of Political and Social Research (ICPSR). Retrieval would also be enhanced if data sets housed in repositories were indexed in bibliographic databases in the same manner as books and periodicals (Kiecolt & Nathan, 1985).

Conclusions

Data sharing is, at present, an ideal rather than a norm in nursing. However, as Clubb, Austin, Geda and Traugott (1985) note, norms of data sharing cannot be established and accomplished by fiat. Rather, a climate in which data sharing is accepted as a norm can only be achieved through discussion and demonstration of the value of data sharing. Unless nurse scholars and researchers are committed to the concept, data sharing is likely to be sporadic and fragmented. Weil and Hollander (1991) effectively summarized some of the normative issues related to data sharing:

> Data sharing cannot be looked at in the abstract but must be viewed as a set of social practices within specific research communities. The practices are governed or constituted by conventions, and the conventions evolve. They respond to internal requirements and opportunities, many rooted in the subject matter. They also accom-modate external demands, such as those of business, government, and other social organizations, public opinion, and cultural change ....Each of these constituencies can play a role that preserves discipli-nary autonomy and helps to make a discipline accountable within itself as well as to outsiders (p. 152).

A decade ago Ceci and Walker (1983) charged that federally funded research was intended to benefit the health and welfare of the public, not to advance individual careers. With this in mind, we have argued for increased

awareness of data sharing among nurse researchers and for the establishment of professional standards to facilitate the incorporation of plans for data sharing into research proposals and programs. We urge Canadian nurse researchers to increase their efforts to collaborate with each other and to provide the leadership and mentorship that will be required to engage in a meaningful debate about the advantages, issues, and challenges of data sharing.

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Acknowledgements

Canadian First Nations Women's Beliefs About Pregnancy and Prenatal Care

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Les faits indiquent le lien entre des soins prénatals appropriés et de meilleurs résultats quant aux naissances. La recherche cependant montre que les femmes autochtones ne participent pas de façon régulière aux soins prénatals. Dans la présente étude, sept informatrices, représentant trois tribus autochtones, ont été longuement interviewées concernant leurs convictions sur la grossesse et leur participation à des soins prénatals. Les femmes autochtones conçoivent la grossesse selon un contexte spirituel et croient qu'il s'agit d'un processus sain et naturel qui ne requiert aucune intervention. Dans la mesure où elles estiment que la responsabilité leur incombe de «s'occuper d'elles-mêmes» pendant leur grossesse, elles font leur les pratiques culturelles censées favoriser une bonne grossesse. Les femmes autochtones semblent souvent insatisfaites des prestateurs de soins de santé dans les cliniques d'accouchements. Souvent, on ne satisfait pas à leurs attentes et leurs convictions par rapport à la grossesse sont en conflit avec celles des prestateurs de soins de santé. On pourrait briser les barrières qui empêchent le recours aux soins prénatals en améliorant la communication et en offrant des soins holistiques axés sur la culture spécifique.

Evidence links adequate prenatal care to improved birth outcomes. Research, however, indicates that First Nations women do not attend regularly for prenatal care. In the current study, seven informants, representing three First Nations tribes, were extensively interviewed to examine their beliefs about pregnancy and participation in prenatal care. First Nations women conceptualized pregnancy in a spiritual context and believed it to be a healthy, natural process requiring no intervention. Since they believed they were responsible for "taking care of themselves" during pregnancy, cultural practices that were thought to promote a healthy pregnancy were espoused. First Nations women were reportedly often dissatisfied with health-care providers in prenatal clinics. Their expectations of freely offered explanations and a friendly non-authoritarian approach were often not realized and their beliefs about pregnancy were in conflict with those of health-care providers. Barriers to prenatal care might be reduced by improving communication and providing holistic culture-specific care.

Considerable evidence links adequate prenatal care to improved birth outcome in Caucasian and various ethnic groups (Graham-Cumming, 1967; Morris, Berenson, Lawson, & Wiemann, 1993). Although it is not the only factor contributing to a healthy pregnancy outcome, it enhances the possibility for appropriate health-related interventions as required.

Research indicates that First Nations women do not regularly attend prenatal care (Baskett, 1977; Graham-Cumming, 1967), despite the fact that they tend to be a high-risk group for several health-related reasons. Baskett (1977) found that 14.3% of First Nations women received minimal prenatal care (fewer than four visits) and 9.2% received none; Graham-Cumming found that 30% made good use of prenatal services, 30% made fair use, while 40% made little or no use of these services. The First Nations population

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tends to have a high incidence of adolescent pregnancy, complications of pregnancy, grand multiparity, low and high birthweight babies, and greater infant mortality following preterm birth (Baskett, 1977; Community Task Force on Maternal and Child Health, 1981). Additional risk factors include inadequate nutrition during pregnancy (Bureau of Nutritional Sciences, 1975), high blood pressure, gestational diabetes, and antepartum bleeding (Wotton & Macdonald, 1981).

Background

Only six studies have explored First Nations women's beliefs and practices related to pregnancy. Hildebrand (1970) and Clarke (1990) focused on the Chippewa of the Great Lakes and the Salish of British Columbia, respectively, whereas other researchers studied American First Nation groups: Navajo (Loughlin 1965), Iroquois (Evaneshko, 1978), and Northwest Coastal (Bushnell, 1981; Horn, 1978) groups.

Reportedly, Canadian First Nations women believe that breaching traditional teachings surrounding pregnancy can result in harmful consequences (Clarke, 1990). Violating food taboos is believed to result in a difficult labour (Clarke, 1990; Hildebrand, 1970) and abnormalities in the baby (Clarke, 1990). Inactivity is believed to cause the placenta to adhere to the uterus (Hildebrand, 1970) or the baby to attach to the womb, resulting in a difficult labour (Clarke, 1990). Sensory experiences of the mother are believed to be passed on to the fetus. Women believe that by "listening" to their bodies they can learn what is beneficial or harmful for themselves and their babies (Clarke, 1990).

Among American First Nations women, pregnancy is believed to be a normal, natural process requiring no intervention (Bushnell, 1981; Horn, 1978; Loughlin, 1965). Little preparation is made for the coming baby (Bushnell, 1981; Loughlin, 1965) because it is believed that illness, injury, or even death of the unborn child could result (Loughlin, 1965). Women believe they give care to their babies through their own good health and nutrition (Bushnell, 1981), and are encouraged to maintain a normal work schedule (Evaneshko, 1978) without any extra support (Bushnell, 1981).

Canadian and American First Nations women identified barriers to prenatal care attendance, including dislike of vaginal examinations (Hildebrand, 1970), lack of continuity of care (Hildebrand, 1970; Horn, 1978), communication difficulties (Hildebrand, 1970), transportation problems (Hildebrand, 1970; Horn, 1978), and attitudes of prejudice on the part of the health-care workers (Horn, 1978). Women questioned the value and need for prenatal care (Bushnell, 1981; Horn, 1978; Loughlin, 1965) and the appropri-

ateness of prenatal classes as a source of information because the family (especially grandparents) has primary responsibility for teaching (Clarke, 1990). In summary, they embrace a natural approach to pregnancy and rely on culturally prescribed practices to maintain a healthy pregnancy.

Factors Associated With Prenatal Care Attendance

Numerous studies have investigated factors associated with prenatal care attendance, although none were based on First Nations women. Socio-demographic variables that have been found to improve attendance were: older age of the mother (Lia-Hoagberg et al., 1990; McDonald & Coburn, 1988), higher education of the mother (Lia-Hoagberg et al., 1990; Parken, 1978), lower parity (Kaliszer & Kidd, 1981; Kieffer, Alexander, & Mor, 1992), married marital status (Collver, Have, & Speare, 1967; McDonald & Coburn, 1988) and employment of husbands (Kaliszer & Kidd, 1981; McKinlay, 1973). Psychosocial factors found to enhance prenatal care attendance include available support, such as verbal encouragement and provision of transportation to appointments (Lia-Hoagberg et al., 1990; Poland, Ager, & Olson, 1987), planned pregnancy (Lia-Hoagberg et al., 1990; McKinlay & McKinlay, 1972), and previous pregnancy complications (McKinlay & McKinlay, 1979; Parsons & Perkins, 1982).

In contrast, several factors have been identified that appear to deter prenatal care attendance: impersonal treatment, long waits to see the doctor, rushed visits (Curry, 1989), fear of medical procedures (Lia-Hoagberg et al., 1990), lack of continuity of nursing care (Poland, 1976), lack of child care, and transportation problems (Curry, 1989; Lia-Hoagberg et al., 1990). Negative feelings toward pregnancy (Watkins, 1968) and fear of pressure from a doctor to have an abortion (Simms, 1984) also have been found to delay prenatal care attendance.

Research Questions

Few studies have investigated the cultural, psychological, and decision-making processes of women seeking prenatal care; notably these were not studies of First Nations women. If prenatal care attendance by First Nations women is to be improved, more research is needed. Therefore, the purpose of the current qualitative study was to explore the health beliefs of Canadian First Nations women regarding pregnancy and prenatal care. The research questions were:

What are the health beliefs of First Nations women about pregnancy?

What are First Nations women's beliefs about prenatal care?

What factors influence First Nations women's participation in prenatal care?

Method

Informants

Seven English speaking key informants residing in a Canadian urban centre, participated in the study. An *N* of seven was considered an appropriate number based on previous studies where six to 12 informants were used to gather qualitative cultural data (Evaneshko & Kay, 1982; Horn, 1978). Informants were selected on the basis of three criteria suggested by Spradley (1979): they were familiar with, and currently involved with the First Nations culture; and they had adequate time. In addition informants were 18 years of age or older, had one or more children, had previously attended prenatal care, and were leaders in First Nations women's health. Informants represented three First Nations tribes located in Canada: Cree (*n*=3), Saulteaux (*n*=2), and Ojibway (*n*=2). One of the seven informants completed only part of the study because she moved to another province; the information was nevertheless included in the analyses. All informants had lived on a First Nations reserve for 8 to 15 years.

After approval was obtained from an Ethical Review Committee, potential informants were telephoned or personally approached and invited to participate in the study. Names of potential informants were obtained from acquaintances of the researcher and from informants who participated in the study. Ten potential informants who met the study criteria were identified and contacted, but three refused to participate.

Data Collection

During the initial interview the study was explained more fully and consent was obtained. Interviews were conducted by the researcher at the informant's convenience in the informant's or researcher's home or the informant's work place. Four to five in-depth, tape-recorded interviews of one to three hours each were conducted with each of the six informants, and one and one quarter hours with one informant, for a total of 45 hours.

An interview guide was developed by the researcher and reviewed by a First Nations nurse with a baccalaureate degree in nursing and two non-First Nations nurses with masters of nursing degrees. The interview guide consisted of general topics such as beliefs about spacing of children, prenatal practices, pregnancy, and prenatal care. Examples of specific questions asked during the interviews were: "What do First Nations women generally think about having children?" and "What do First Nations women think are things that are good for them and their babies during pregnancy?" Initial interviews were based on the interview guide, but as concepts and themes for further exploration emerged, these became the focus of subsequent interviews. For example,

when some informants began discussing support for single mothers, this topic was explored.

The tape-recorded interviews were transcribed verbatim and content analysis was used to code the data and identify themes and categories (Holsti, 1969). In the development of categories, frequency counts were used. Thus, if four or more informants concurred on a belief, this was subsumed as a category under a particular theme.

Findings

Seven major themes were identified from the interviews. These related to beliefs about pregnancy, children, spacing of children, helpful prenatal practices, harmful prenatal practices, prenatal care, and interactions with health-care providers.

Beliefs About Pregnancy

Traditional beliefs were those that informants identified as being part of their culture. Informants consistently stated that pregnancy is traditionally believed to be a blessing from the creator. "And if you were pregnant...that was a blessing for you....You were being blessed and you were chosen to carry this new baby." Because pregnant women are believed to be carrying extra life for the creator and because of changes and risks associated with childbearing, pregnant women are respected and hold special status in First Nations society.

First Nations women also believe pregnancy to be a natural process, maintained by nature and requiring no interference:

> It's seen as a very natural process. It's nature....the nurturing is done by Mother Nature. And of course the baby is taken care of by nature in a similar way. And you don't want to interfere too much with the growth.

Informants cited indicators of pregnancy such as a missed period, morning sickness, and weight gain. Some women "just know" that they are pregnant before any signs appear due to a "feeling" they have. It also is believed that pregnant women have a certain look in their eyes. "My mother was saying that there is that certain spark or twinkle in the eyes. That is because of this new life that is beginning inside you."

Informants unanimously stated that pregnancy is not believed to be a sickness. "Grandma will teach that it's [pregnancy is] not a sickness. It's a natural process." Most also thought that First Nations women believed they were not susceptible to sickness during pregnancy; half reflected the view that

sickness during pregnancy was not serious, while the rest thought that sickness during pregnancy could be somewhat or very serious. "No, it [pregnancy] is considered such a normal process that you would not anticipate problems or difficulties unless there is some previous experiences."

The conceptualization of pregnancy as a normal, natural process was also evident from First Nations women's beliefs about who should attend them during childbearing. It was believed that attendants during pregnancy and childbirth should be older, experienced women, not doctors, although physicians are considered appropriate consultants for medical problems. Men are believed to be harmed by participating in pregnancy-related affairs.

> I was told it's a woman's role and it's not for a man to be there when a child is being born because that can affect the man as well.... The reason it could be harmful to the man is because of the power behind it.

Beliefs About Children

Children are considered to be a gift from the creator and each one is welcomed and treasured. Although it is believed that marriage should precede childbearing, it is thought that mothers should keep out-of-wedlock babies. Unwed mothers and their children tend to be accepted and supported.

Another belief is that the role of parents is only temporary. Parents have a responsibility to care for a child for the creator until the child becomes independent. First Nations people believe the responsibility for children should be shared by the entire community. The application of this concept is evident in the case of the childless couple. It is common for a family member or friend to offer their own child for adoption by a childless couple.

Beliefs About Spacing Children

Traditional First Nations women's beliefs about spacing children are linked to their view of pregnancy as a natural process and a blessing from the creator: people "should not specify the number of children to have," but rather children should be accepted naturally as they come.

Childbearing is closely aligned with womanhood. "You are a woman and a woman is made to have children, to have babies, and if you don't have babies, then you are looked at as being not really a woman." As a consequence a tubal ligation and hysterectomy are unacceptable to traditional First Nations women. Since life is believed to begin at conception, therapeutic abortion is also not accepted. ("It's almost like saying you got rid of that life you were blessed with.") Guilt and an inability to bear future children are thought to be consequences of having an abortion.

However, informants concurred that beliefs about spacing children have changed and some women now choose various available methods to limit family size. It is believed to be a woman's decision to have children or to take measures to prevent pregnancy.

Among urban-dwelling women, a range of two to four children is currently considered ideal with a period of one to five years between pregnancies. Breast-feeding is believed to be an effective method of birth control. Herbal preparations, which are considered natural, are used by some First Nations women to prevent pregnancy.

Helpful Prenatal Practices

First Nations women believe that various practices implemented by the expectant woman will promote a healthy pregnancy. Women are responsible for "taking care of themselves" so that the outcome of pregnancy will be a healthy baby. This was illustrated by an informant when she described the advice of an elder to a pregnant woman: "...take care of yourself as the way that the creator would want you in order for your child to be healthy....You don't drink, you don't smoke, you eat properly and that type of thing." Women believe that miscarriages and preterm births result when they do not take care of themselves during pregnancy.

A well-balanced diet and moderate portions are believed to help maintain a healthy pregnancy. Foods such as wild meat or fish, white carrots, potatoes, rice, and berries are thought to be particularly beneficial. Exercise in moderation is believed to be a healthy practice during pregnancy. Walking is thought to be particularly suitable because groups of First Nations people walked from camp to camp. Adequate rest, sleep, and quiet times are also thought to be important.

It is believed that the mother's emotions can be transmitted to her baby during pregnancy. As a consequence, expectant women are encouraged to have positive, pleasant thoughts during pregnancy and to communicate with the baby.

Harmful Prenatal Practices

First Nations women believe that during pregnancy strenuous activity, consumption of chemical substances such as alcohol and drugs, and smoking can endanger the health of a mother or baby.

Informants unanimously stated that strenuous maternal activity is thought to result in miscarriages or preterm births. Controlled breathing and physical exercises (such as those taught in prenatal classes) are believed to affect the baby adversely; no further explanation of consequences was offered.

Consumption of alcohol during pregnancy is believed to cause miscarriage. Smoking is also considered harmful, although no explanation of the harmful effects had been given by those who taught the women. Traditional First Nations women believe that taking medications during pregnancy is unnatural.

Technological interventions during pregnancy are believed to be detrimental and some women are fearful of them. Ultrasound, for example, is thought to affect the baby's development, delay delivery, and interfere with the communication between mother and baby. Artificial induction of labour, fetal monitoring, pelvic examinations, and the use of obstetrical forceps are also considered harmful interferences.

Beliefs About Prenatal Care

Some First Nations women believe that prenatal care is beneficial, but many perceive no benefits. They think that the frequency of visits during normal pregnancies could be reduced, but increased if complications arise: women should develop a pattern of attendance based on their own perceived needs.

Informants specified that the primary factor enabling prenatal care attendance was the belief that problems would be identified and treated so the outcome would be a healthy baby. Problems encountered in a previous pregnancy would be a factor strongly motivating women to attend prenatal care.

The primary factors limiting prenatal care attendance were a lack of babysitting services and the absence of past or current problems during pregnancy. Informants consistently identified the prospect of pelvic examinations as being a deterrent, especially if performed by a young male doctor; an older female doctor was preferred. An additional limiting factor was the belief that staff would pressure women into having an abortion. One informant recalled: "I thought maybe the doctor might want to talk me out of my pregnancy.... So I stayed away from the doctor for as long as I could."

Interactions With Health-Care Providers

First Nations women believe that communication with staff during prenatal care visits is less than ideal, yet they desire positive interactions. They find such appointments to be rushed, cold, and impersonal, with long waiting periods to see the doctor. Satisfying visits occur when staff offer explanations freely and a friendly non-authoritarian approach is taken. The following narrative by an informant illustrates a personalized caring approach:

> The nurse would come in there and tap somebody on the shoulder ...and say, "How are you?" You know that touch on the shoulder is a connection to say you are important too. And she would tell them

who she is and shake hands with them. So she'd introduce herself to them.... And then she would...sit there and talk to them.... It's almost like she centred her whole attention on you. It really made you feel comfortable. All of a sudden she made you feel you are so important.

According to the informants, First Nations women are characteristically shy and reluctant to ask questions during prenatal visits. They believe it is inappropriate for others to ask them too many direct questions or to discuss personal matters such as their menstrual periods.

You don't talk about your periods, your menstrual cycle.... If you ask a woman when was her last menstrual period, they will just ignore you. They will not look at you, they will not respond, they will just clam up.... They would become embarrassed and they would become uncomfortable.

First Nations women tend to refrain from giving feedback to staff and generally do not express satisfaction with care. Dissatisfaction with care is customarily expressed to a third person, who in turn discusses the situation with the health-care worker involved.

Some First Nations women tend to identify the timing of events by occurrences in nature, rather than stating a precise date (e.g., they may identify the date of their last menstrual period as being when the leaves started to come). As described in the following excerpt, nonverbal communication is believed to be more critical than verbal communication.

Indian people communicate very much through body language and they also look at how the next person behaves through their body language. We refer more to their actions.... It has so much weight. More so than any words that you can say, is the way that your actions are.

Discussion

The current study had two major limitations. Non-English-speaking First Nations women, whose beliefs may be different from those who are English-speaking, were excluded. Additionally, since three different First Nations tribes were represented by seven informants, there were too few representatives of each tribe to examine inter-group differences.

Results indicate that discrepancies exist between the beliefs of First Nations women and those of health-care providers. The former explain pregnancy in a spiritual context. This is a basic concept underlying many of the explanations they give for behaviours and practices related to pregnancy and

for their attitudes towards children. Pregnancy is viewed as a natural, normal process requiring no intervention. Similarly, Bushnell (1981), Horn (1978), and Loughlin (1965) found that First Nations women question the need for prenatal care. Clarke (1990) also found that First Nations women believe in "no change required" during pregnancy. In contrast, health-care providers in Canadian society (especially male medical personnel) often view pregnancy as a medical event. In a study of four national cultures Jordan (1980) found that American health-care providers view pregnancy as a medical event and take a technological approach in managing pregnancy and birth. As revealed in the current study, some First Nations women do not believe they are susceptible to serious illness during pregnancy, whereas health-care providers focus much of their care on monitoring for complications of pregnancy. These cultural differences may be obstacles to effective inter-ethnic relations (Boyle & Andrews, 1989), and signs of conflict and stress may occur if health personnel impose their ideas and practices upon clients (Leininger, 1991).

The current study reveals that spiritual, social, and psychological factors motivate First Nations women to bear children, and that womanhood is closely linked to childbearing. Horn (1983) also found that American First Nations teenagers believed the feminine role to be most clearly identified through pregnancy and childbirth.

The barriers to prenatal care attendance cited in the current study were babysitting problems, the belief that attendance is required only in the event of present or past problems with pregnancy, and dislike of pelvic examinations. First Nations women in Hildebrand's (1970) research also delayed initiating prenatal care because of dislike of vaginal examinations.

The current findings indicate that healthy prenatal practices such as a well-balanced diet, walking, avoidance of stress, and adequate rest and sleep are advocated. Bushnell (1981) and Evaneshko (1978) also found that First Nations women are encouraged to walk during pregnancy and to avoid emotional stress. So why do First Nations women have birth outcomes that tend to be unhealthy? This is a complex issue. Two possible factors may be the loss of traditional lifestyles because of social change, and poverty with its attendant stress. Furthermore, cultural beliefs may be espoused without being acted on. For example, women may believe that foods from the land provide a healthy diet during pregnancy but have no access to such foods. Perhaps health-care providers need to place more emphasis on promoting healthy traditional practices and reducing poverty in order to enhance pregnancy outcomes.

Because the current study was exploratory in nature, it would be premature to draw from it any implications for nursing. However, informants did offer recommendations for improving prenatal care attendance: interactions

in prenatal clinics should be enhanced by providing non-authoritarian, individualized care in a quiet, unhurried fashion. Consideration should also be given to providing nurse-midwifery services, First-Nations health-care workers, and continuity of health-care workers.

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Book Reviews

Reviewed by: Marcia Beaulieu

John Rolland has consolidated and elaborated several of his previously pub-
lished ideas into a generic model that practitioners may use to enhance the
competence and mastery of families faced with any chronic illness. The major
premise of the resulting Family Systems-Illness model is that both health
professionals and families need to understand how dimensions of illness
interact with family variables. An overview of the model is presented in the
introduction of his new book. Part one describes the two main features of the
model's illness component—a psychosocial typology and time phases of illness.
The concept of uncertainty overarches both. The psychosocial typology of
illness is derived from the assumption that different combinations of the
onset, course, outcomes and incapacitation of illnesses make different demands
on families. The crisis, chronic and terminal time phases are thought to pose
additional challenges to those brought on by an illness' natural history. Thus,
the terminal phase of a life threatening illness that began with an acute onset
and rapidly deteriorating course, will have quite a different effect on families
than a relatively stable illness with a gradual onset and long remissions.

Part two focuses on the model's second major component—features of fami-
lies that mediate the impact of illness. Here Rolland describes family processes
and influences such as family health beliefs, family life cycle and intergenera-
tional factors that may impinge on families' adaptability to chronic illness.
His skilful assessments and interventions effectively remind the reader that his
systems approach includes illness, individual, family and health professional.
Part three deals with issues of treatment and intervention.

The model's strengths lie in its theoretical and clinical underpinnings, its con-
ceptual coherence and a level of complexity that does justice to the phenomenon
under study. Rolland has masterfully integrated and built on existing empiri-
cal and theoretical literature on the family from anthropology, sociology, nurs-
ing, social work, psychology and psychiatry, often in quite innovative ways.
For example, he creatively fuses Levinson's life structures and transitions
with notions of periods of greater or lesser family cohesion. He then considers

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variations in the impact of chronic illness when different combinations of these factors are operating. His choice of concepts and their interrelations are well grounded in his personal family experience and clinical consultations with some six hundred families. From the literature and his sensitive observations he convincingly constructs a richly complex but coherent whole. Finally, the model is sufficiently well articulated so that others could further test it clinically to evelute its strengths and limitations.

This should prove a valuable sourcebook for both seasoned clinicians and beginners in any health discipline. It is well illustrated with examples, case studies, diagrams, tables and interesting suggestions for applications of the model. Although Rolland writes with great clarity, the multi-textured character of the model invites frequent reflection during reading. It is a book that one will surely return to often and find more with each reading.

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La Santé et la Famille—Une approche systémique en soins infirmiers. Sous la direction de Fabie Duhamel. Montréal: Gaëtan Morin, 1995. 259 pp., index. ISBN 2-89105-559-4.

Recension par Suzanne Caty

Les infirmières ont toujours reconnu le rôle important que joue la famille dans l'expérience de la maladie de l'un de ses membres ainsi que l'impact de cette maladie sur la famille. Ce livre longtemps attendu élabore, d'une façon claire, une approche systémique qui guide l'infirmière dans les soins auprès de la famille faisant face à une problématique de santé. L'auteure principale, nous présente un livre sur la santé et la famille, livre qui sera utile à toutes les infirmières travaillant auprès des familles francophones.

Le volume est divisé en deux parties. Dans la première partie on y retrouve quatre chapitres écrits principalement par Duhamel. Ces chapitres visent à nous familiariser avec les connaissances théoriques et les recherches sur lesquelles s'appuie l'approche systémique. Au premier chapitre, l'auteure utilise des écrits pertinents et récents pour décrire la relation entre la problématique de santé et la famille. Elle élabore, très tôt dans le chapitre, une définition claire de la problématique de santé. Au deuxième chapitre, nous retrouvons l'élaboration des concepts majeurs que l'infirmière doit utiliser dans l'approche

Suzanne Caty est professeure titulaire et directrice à l'école des sciences infirmières de l'Université Laurentienne à Sudbury, Ontario.

systémique auprès de la famille. L'auteure y discute brièvement des théories qui sous-tendent cette approche.

Au troisième chapitre, l'auteure décrit en détail le modèle d'évaluation familiale de Calgary ainsi que les théories qui ont inspiré le développement du modèle. À travers ce chapitre l'auteure utilise aussi des écrits pour expliquer les différentes composantes du modèle de Calgary. À la fin du chapitre nous retrouvons des exemples de questions qui peuvent être utilisées dans des entrevues avec des familles. Au quatrième chapitre, l'auteure décrit des interventions systémiques que nous pouvons employer. Ces interventions sont basées sur la croyance que la famille a la capacité et la compétence pour résoudre les difficultés auxquelles elle fait face. Au cinquième chapitre, Bell et Wright nous lancent le défi d'axer notre recherche sur l'efficacité de nos interventions avec les familles. Ces auteures utilisent des exemples de leurs recherches et interventions auprès des familles pour appuyer leur position.

Ces premiers chapitres sont très bien écrits et sont relativement faciles à suivre. Ce texte sera sûrement très utile aux étudiantes du deuxième cycle. Il est possible que les étudiantes au niveau du baccalauréat aient quelques difficultés à comprendre certaines parties de ces chapitres. Il serait alors important que les professeures qui utilisent ce livre dans un cours en soins infirmiers auprès des familles trouvent des moyens pour faciliter la compréhension de cette approche.

Dans la deuxième partie, neuf auteures ont collaboré dans le développement de situations cliniques où l'approche systémique est employée auprès de familles faisant face à une problématique de santé. Ces exemples sont liés à différentes étapes du cycle de la vie familiale et à différents domaines cliniques. Pour chaque situation clinique, les auteures ont situé la problématique de santé dans le contexte de théories et d'écrits pertinents. Les exemples sont très bien élaborés et nous aident à voir comment l'approche systémique et les théories sous-jacentes ressorties dans la première partie du livre peuvent être utilisés dans notre pratique. Les étudiantes, les cliniciennes et même les professeures profiteront sûrement de ces exemples.

En résumé ce livre répond à un besoin très réel dans les soins infirmiers. La réforme des soins de santé qui met de plus en plus l'accent sur la participation active des familles dans les soins de santé exige que nous soyons conscientes de la relation entre la problématique de la santé et la famille. Ce livre nous permet d'augmenter nos connaissances et nos habiletés sur ce sujet.

◆

Sourcebook of Family Theories and Methods: A Contextual Approach. P. Boss, W. Doherty, R. LaRossa, W. Schumm, & S. Steinmetz (Eds). New York: Plenum Press, 1993. 748 pp. ISBN 0-306-44264-7.

Reviewed by Kathleen M. Rowat

This book might best be described as a "gold mine" for those with an interest in the family. Following on the earlier works of Christensen (1964), Burr et al. (1979) and Sussman and Steinmetz (1987), the editors of the present volume aim to "capture the spirit of family studies in the 20th century" and to prepare researchers, practitioners, and educators for the century to come. Seventy-three contributors, representing a wide variety of disciplines, have assisted in the preparation of this work.

As noted in the preface, a number of features differentiate this book from previous efforts of "stocktaking" family studies. First, there is a focus not only on family theories but also on research methods and the relationship between the two. Secondly, the reader is provided with the sociohistorical context within which the theory and method were developed. A further unique feature of the volume is the inclusion of chapters dealing with the application or implementation of the theories for practice, education and policy. Finally, issues such as age, ethnicity, race, and gender, which to a large extent have been overlooked in previous compilations of family theories, are addressed.

The book is divided into seven parts. Part I provides an overview of the sociocultural and historical contexts within which family theory and associated research methods developed in the twentieth century. Graduate students, in particular, will welcome those sections dealing with definitions and types of family theories and the criteria by which such theories might be judged. While acknowledging the possibility of factions developing within the field of family study and the ever present temptation to reject the past, the authors of this first chapter call for an openness and flexibility of thinking in order that Family Science move forward. It is on this optimistic note that the reader is led to explore the history of the development of Family Science up to and including the 1980s.

Part II discusses the emergence of family theories and methods beginning with the classics. The reader is taken through an exciting historical journey of the roots of family theorizing, beginning with the writings of Plato, Aristotle

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and Rousseau. The remaining five sections of the book are organized chrono-logically, looking at family theories and methods as they emerged during the decades beginning with 1918 and concluding with the 1980's. The inclusion in the final section of the book of topics such as the place of feminist theories in the development of Family Science and the biosocial perspective on fami-lies underscore the completeness and comprehensiveness of this volume.

As suggested by the title of this book, this is indeed a Sourcebook. Although readers would be wise to read Part I of the book i.e. the Overview, in order to acquaint themselves with the overall orientation and organization of the book, the subsequent sections essentially can stand alone allowing, therefore, the family scholar to delve into those topics of particular interest to him/herself. This book should be considered a must for those concerned with the develop-ment of Family Science.

Happenings

Talking the Talk—and Walking the Walk: Community Development in Western Manitoba

John C. B. English

How can an association concerned with death and dying be a healthy community project? Well, when one considers that a characteristic of a healthy community is that its members are concerned and caring enough to help each other through life's crises (English & Hicks, 1992, p. 63), how could it be considered anything else?

The impetus for forming WATCH, which is an acronym for Westman Association for Terminal Care in Hospice, arose out of the Healthy Community philosophy espoused by VisionQuest, Brandon's Healthy Community project. WATCH was born in 1992 out of the need for palliative care beds expressed in protest letters to the editor in the Brandon Sun. The Brandon General Hospital had virtually closed the palliative care unit in response to severely curtailed funding by the Manitoba government. A public meeting resulted in an intersectoral study group being formed to examine the need for hospice services here and found that this need extended to all of Westman. This finding resulted in the formation of WATCH. Membership in the organization has grown throughout the region.

Operating within the Westman region, WATCH exists to sustain dying persons and their families by providing a caring community in which patients may live life to the full, and bereaved families are supported into the future. This mission is carried out by offering support to terminally ill patients and their families and friends either in a residential hospice facility, in their own homes, or both. Specifically the goals are to:

◆ educate the public about the need for hospice and home care for the terminally ill,

◆ provide support for terminally ill people and their family and friends within the home environment,

John C.B. English, R.N., M.Sc.N., is Associate Professor in the Department of Nursing and Health Studies at Brandon University, Manitoba.

- establish a free-standing hospice (a homelike residence for dying people),
- provide opportunities for education of volunteer hospice workers,
- establish and maintain contacts with those groups concerned with the provision of terminal care,
- maintain sufficient funds for the establishment and maintenance of facilities and programs for the terminally ill,
- maintain membership in good standing in the Manitoba Hospice Foundation.

Membership in WATCH now stands at nearly 200. A Board of Directors, elected by the membership, and six standing committees administer all the work entailed in meeting the above goals. The task is enormous for a group of volunteers alone. Because of this, the Board has hired the services of a Coordinator of Volunteers, Susanne Hunt, to provide consistent organization and support, especially in meeting client care needs. Thousands of hours of volunteer time have been devoted to establishing and providing hospice services since the organization's inception.

WATCH first undertook the education of its volunteers. These volunteers are now providing service in the homes of families affected by terminal illness. The number of clients receiving care varies from month to month; ten families were attended to last month. WATCH is becoming established within the community as a credible agency that can accept referrals and provide valuable assistance. Linkages with the Brandon General Hospital and Home Care services are building bridges that enable WATCH to enhance the care received by families at this critical life stage. We are also providing bereavement follow-up to a group of twenty-five adults, and to a group of four children. A group of four adolescents will be started in the near future.

When we have a suitable facility, and a sufficient number of trained volunteers, we would like to start a Day Program for people living with terminal illness in their own homes. By bringing people together, this program will help to provide physical and emotional support, and the social contracts so necessary if one is to live life to the full. The tedium of being at home and sick can be very wearing to all concerned. This lighthearted program will provide respite for both the patient and his or her care-giver.

WATCH has yet to raise sufficient funds to establish a free-standing hospice. This difficult task is being worked on with energy and enthusiasm. Thanks to donations from individuals and organizations such as service clubs, churches and businesses we are steadily moving closer to that goal.

References

English, J.C.B., & Hicks, B. (1992). A systems in transition paradigm for healthy communities. *Canadian Journal of Public Health, 83* (1), 63-65

Reviewers/Lecteurs **Volume 26 – 1994**

The Canadian Journal of Nursing Research is indebted to the persons below who served as reviewers for Volume 26 of the CJNR. Their names were inadvertently omitted from the list appearing in Volume 26, No.4. They gave generously of their time and shared their knowledge and in so doing have contributed greatly to the editorial process and to the development of nursing knowledge.

La Revue canadienne de recherche en sciences infirmières est reconnaissante envers les personnes ci-dessous nommées d'avoir révisé son volume 26. Regrettablement, leurs noms étaient, par mégarde, omis de la liste qui était publiée dans le volume 26, no.4. Ces personnes ont généreusement donné de leur temps et partagé leur savoir. Ce faisant, elles ont largement contribué au processus éditorial et au développement des connaissances en sciences infirmières.

Acute Care

Winter 1995 (vol. 27, no.4)

Topics such as the individual's and families' response to illness, new approaches to care, the impact of new technology, and interdisciplinary approaches are welcome. Priority will be given to research reports. However, review articles will also be considered.

Editors: Dr. Mary Grossman and Dr. Laurie Gottlieb
Submission Deadline: August 15, 1995

Culture & Gender

Spring 1996 (vol.28, no.1)

Papers are invited that address the theoretical and methodological issues in conducting cross-cultural research. We are especially interested in receiving articles from a feminist perspective, that attempt to examine the intersection of gender, race and class in the conduct of nursing research, and that outline strategies for the utilization of research findings.

Guest Editor: Dr. Joan Anderson
Submission Deadline: October 15, 1995

Symptom Management

Summer 1996 (vol.28, no.2)

Manuscripts are invited that address management of symptoms. Symptoms may include, but are not limited to, pain, discomfort, nausea, anxiety, depression, and confusion. We seek a wide range of patient populations, symptoms, and management strategies. Preference will be given to completed research reports.

Guest Editor: Dr. Celeste Johnston
Submission Deadline: December 15, 1995

Please send manuscripts to:
The Editor,
Canadian Journal of Nursing Research,
McGill University School of Nursing,
3506 University Ave., Montreal, Qc H3A 2A7

Soins Aigus

publication: hiver 1995 (vol. 27, no.4)

Vous êtes invités à nous soumettre des articles portant sur les soins aigus. Les sujets peuvent concerner, entre autres, l'existence de nouvelles approches de soins, l'impact de nouvelles technologies, les réactions à la maladie, l'implication du malade et de la famille et la collaboration interdisciplinaire. Les rapports de recherche auront la priorité. Cependant, les articles critiques seront également pris en considération.

Rédactrices: Dre Mary Grossman et Dre Laurie Gottlieb
Date limite pour les soumissions: le 15 août 1995

La Culture et le Sexe

publication: printemps 1996 (vol.28, no.1)

Les articles porteront sur les questions théoriques et méthodologiques dans la recherche intercultlurelle. Nous aimerions surtout des articles rédigés dans une optique féministe, qui tenteront d'examiner le croisement du sexe, de la race et de la classe sociale dans la recherche en sciences infirmières, et qui mentionneront des stratégies pour l'utilisation des résultats de la recherche.

Rédactrice invitée: Dre Joan Anderson
Date limite pour les soumissions: le 15 octobre 1995

La Gestion des Symptômes

publication: été 1996 (vol.28, no.2)

Nous vous invitons à soumettre vos manuscrits sur le traitement des symptômes. Ceux-ci comprendront, sans s'y limiter, la douleur, l'inconfort, la nausée, l'anxiété, la dépression et la confusion mentale. Nous désirons étudier un large éventail de symptômes, de stratégies de traitement et de types de malades. Les rapports de recherche complets auront la priorité.

Rédactrice invitée: Dre Celeste Johnston
Date limite pour les soumissions: le 15 décembre 1995

Prière de faire parvenir les manuscrits à la :
Rédactrice en chef
Revue canadienne de recherche en sciences infirmières
École des sciences infirmières de l'Université McGill
3506, rue University, Montréal (Québec) H3A 2A7

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Applicants must have completed a Bachelor's Degree, satisfy the general requirements for admission to the Faculty of Graduate Studies, and be licensed to practice as a registered nurse in Canada or in a foreign country. Admission is based on assessment of professional experience, previous academic work, letters of reference, GRE, and TOEFL for foreign students.

For further information, please contact the Associate Director, Graduate Program, School of Nursing, or the Director, School of Health Services Administration, Dalhousie University, Halifax, Nova Scotia, B3H 3J5.

Assistant Professorships

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The University of British Columbia invites applications for two tenure track faculty positions in the School of Nursing. A doctorate degree in Nursing or a related discipline (earned or near completion) is required; a master's degree in Nursing is also requried. Candidates must be eligible for registration with the RNABC. Applicants should have relevant recent teaching and clinical experience in community health, mental health or adult health nursing. Professional practice and research expertise in one of the following areas is particularly desirable:

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UBC welcomes all qualified applicants, especially women, aboriginal people, visible minorities and persons with disabilities. In accordance with Canadian Immigration requirements, priority will be given to Canadian citizens and permanent residents of Canada. Applications, accompanied by a curriculum vitae and the names and addresses of three references, should be sent by August 31, 1995 to:

Dr. Katharyn May, Director
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University of British Columbia
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Information for Authors

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

Procedure: Three double-spaced typewritten copies of the manuscript on 8½ x 11" paper are required. Articles may be written in French or English. Authors are requested not to put their name in the body of the text, which will be submitted for blind review. Only unpublished manuscripts are accepted. A written statement assigning copyright of the manuscript to *The Canadian Journal of Nursing Research* must accompany all submissions to the journal. Manuscripts are sent to: The Editor, *The Canadian Journal of Nursing Research*, McGill University, 3506 University Street, Montreal, Qc H3A 2A7.

Manuscripts

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

Title page: This should include author(s) name, degrees, position, information on financial assistance, acknowledgements, requests for reprints, address, and present affiliation.

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

Text: The text should not exceed 15 double spaced typed pages. References, tables, and figures should follow the text.

References: The references are listed in alphabetical order, double spaced and placed immediately following text. Author names and journal citations must be spelled out in full.

Tables and Figures: Tables and figures should only appear when absolutely necessary. They must be self explanatory and summarize relevant information without duplicating the content of the text. Each table must include a short title, omit abbreviations and be typed on a separate page. Figures must be in camera-ready form.

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

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Renseignements à l'intention des auteurs

La revue canadienne de recherche en sciences infirmières paraît quatre fois par année. Son mandat est de publier la recherche en sciences infirmières qui développe les connaissances de base dans la discipline et qui analyse la mise en pratique de ces connaissances. La revue accepte aussi des articles de recherche reliés à l'enseignement, l'histoire, et accueille des articles ayant trait à la méthodologie, la théorie, et l'analyse qui promouvoit le développement des sciences infirmières. Les soumissions de lettres et de commentaires sur des articles publiés sont aussi encouragées.

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Tous les manuscrits doivent se conformer à la quatrième édition du *Publication Manual of the American Psychological Association*. Les articles de recherche doivent suivre les consignes énoncées dans le "APA" en guise de présentation de la littérature, des questions de recherche et d'hypothèses, de la méthode, et de la discussion. Tous les articles doivent obéir au manuel "APA" pour les références, les tableaux, et les schémas. N'employez pas de notes au bas de la page.

Page titre: Elle devrait inclure le nom, l'adresse et l'affiliation de l'auteur ou des auteurs, les diplomes obtenus, information sur l'aide financière obtenue, remerciements, demande de copies.

Résumé: Les articles de recherche doivent être accompagnés d'un résumé de 100 à 150 mots, incluant l'objet de la recherche, la conception, l'échantillon, les résultats et les implications. Les manuscrits de théories et de critiques doivent inclure une déclaration des arguments principaux, la structure d'analyse, et un résumé de la discussion.

Texte: La longueur acceptable d'un article n'excède plus que 15 pages. Les articles peuvent être rédigés soit en anglais, soit en français.

Références: Les références doivent paraître en ordre alphabétique, à double interligne, et doivent suivre le texte. Les noms d'auteurs et les citations de revues doivent être épeler entièrement.

Tableaux et schémas: Les tableaux et schémas doivent paraître seulement si nécessaire. Ils doivent résumer des informations pertinentes sans redire le contenu du texte. Chaque tableau doit inclure un court titre, opprimer les abréviations et doit être dactylographié sur une page à part. Veuillez remettre les originaux des schémas, qui doivent être dessinés à l'encre de Chine et prêts à photographier.

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Copie électronique: Les auteurs doivent remettre une copie acceptable de l'article sur disquette de l'acceptation finale de l'article.

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