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Abstract: The stress-coping paradigm: Complementary contributions of social sciences and nursing in the development of professional knowledge

Francine Ducharme

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Focus: *Chronicity*

GUEST EDITORIAL

Trajectories and Transferability: Building Nursing Knowledge about Chronicity

Sharon Ogden Burke

This first chronicity issue of the *Canadian Journal of Nursing Research* recognizes a shift in the generation of nursing knowledge from bio-medical, illness, and disease models (exemplified by "a diabetic patient") to psychosocial, educational models (exemplified by "a person with diabetes" or, more broadly, "a person with a chronic condition"). Behind this shift is a generic view of chronicity, one which posits that the psychosocial issues shared by individuals across hundreds of medical diagnostic groups outweigh those that are unique and bio-medically based (Perrin et al., 1993). The psychosocial model recognizes the importance of the *effect* of the condition on the individual, as opposed to the condition alone. For example, it is from this generic perspective that Magyary and Brandt view children and their families as they cope with chronic conditions.

The shift to generic views of chronicity has not been absolute. Nearly all nursing researchers sensibly still report the disease categorizations of their subjects, while at the same time designing their research and discussing their findings with a view to generalizing to a broader population of persons with similar chronic conditions. This approach assumes that a generic view might be too simplistic and that abandonment of the medical categorizations might be premature. Generalizing about chronicity issues might be well served by the more multidimensional concept of illness trajectory. For example, Ellerton, Stewart, Ritchie, and Hirth studied children with three types of medical diagnoses in order to sample a range of illness trajectories.

The concept of chronic illness trajectory includes notions of direction of the short- and long-term course, the relative stability, and the degree of uncertainty about the course of the condition. Various groupings of trajectories that have been proposed include progressive, constant, relapsing, and episodic (Rolland, 1987; White & Lubkin, 1995; Wong, 1993).

Two promising outcomes for knowledge development in nursing are implicit in the trajectory concept. First, trajectories could provide a way of grouping myriad chronic conditions into a smaller set of trajectories. Thus we would not need to replicate the same study with every possible medical diagnostic population before using descriptive findings with persons with similar trajectories. Hernandez's research, which is reported in this issue, concerned persons with diabetes; one wonders whether her findings might have relevance for persons with similar trajectories – for example, those with renal disease.

The second implicit advantage for knowledge development is that similar trajectories might have common sets of nursing diagnoses and interventions. This is an attractive notion: experimental research with a group of persons with one medical diagnosis could have relevance for persons with other diagnoses, to the extent that they have similar trajectories.

However, researchers and evidence-based practitioners of nursing have been hesitant to make such leaps of logic for fear of overgeneralizing, influenced as we are by the logical positivist's view of such generalizing across medical diagnoses. When rigidly applied to research with persons with chronic conditions, direct clinical applicability of findings would be possible only after experimental research demonstrated cause-effect relationships in randomly selected samples from defined populations. Few can accept such a limited view. Furthermore, the logistics, time, and expense of replication of every study with persons in hundreds of other diagnostic groups would be daunting. More seriously, exclusive use of this approach would bias and limit knowledge generation, by restricting study to medical diagnostic groups that are sufficiently large in numbers. Sampling protocols based on logical positivist principles tend to exclude persons with less common medical diagnoses and persons with multiple problems, such as those with associated mental-health or learning problems. This creates a new generalizability issue, because the true population of persons with chronic conditions can never be sampled with strict adherence to this view.

An alternative concept to the logical positivist's generalizability construct is Lincoln and Guba's (1985) transferability. Transferability of research findings to clinical practice is judged by the user of the findings based on the fit of the sample and the findings to the practitioner's clients. Using the yardstick of transferability rather than generalizability as a guide, trajectories of chronic illnesses offer even more promise for knowledge generation.

It is tantalizing to imagine that transfer of research-based nursing knowledge might be possible across persons with similar trajectories but dissimilar medical diagnoses. So why has trajectory not replaced medical diagnosis in identifying populations for our nursing research? I suspect the answer lies, to a large extent, in how we recruit subjects within a biomedically oriented system.

Beyond the logistics of recruitment, there are still caveats to the transferability of research findings across medical diagnoses, but within trajectories. Age, stage or phase of the illness, and the nature of current stresses and tasks are factors that are apt to impinge on the applicability of the construct of transferability.

The age and developmental stage of the person with a chronic condition, and probably that of their family caregiver, can be expected to influence or override the notion of trajectory. It is not logical to extend the notion of trajectory to very young children or to others who cannot project into the future. At times, a parent's notions of their child's trajectory might be more relevant than those of the child.

It would be logical to hypothesize that the client's view of their condition's trajectory is most salient for nursing research when their current tasks or stresses are of a psychosocial nature. Nursing diagnoses that are predominantly psychosocial in content might be more apt to cluster under illness trajectories than nursing diagnoses that are pathophysiologically based. It would follow that a trajectory framework might be most suitable to nursing interventions that involve psychosocial support.

During acute phases – to the extent that the pathophysiological issues are paramount – an illness trajectory framework might not be as salient for our research or practice. Trajectories might not come into play during the course of initial diagnosis or acute exacerbations, for two reasons. First, pathophysiological issues are paramount. Second, trajectory is a cognitive construct that takes a person time to develop and bring into play. Thus in the early phases of a person's awareness of having a chronic condition, such as learning of the diagnosis and learning about treatment, biomedical frameworks might be in the forefront.

However, as soon as the “long haul” (Rolland, 1987) of coping with the condition becomes the primary issue, trajectories may become relevant.

Our conceptual frameworks on death and dying could be viewed as a phase in chronic illness trajectories, although they have not traditionally been seen as such. In the context of a person’s trajectory, the final phases of illness are very well described compared with the long haul of coping with a chronic condition.

The next steps in building nursing knowledge about chronicity include synthesizing reviews of completed research, definitions, and measures of trajectories, and then using the concept of trajectories to inform subject selection. I suspect that common themes could be teased out of existing research through systematic reviews and synthesis of findings concerning persons with similar illness trajectories. Such systematic reviews will be hampered by a lack of information on the subjects’ trajectories and will speculate, primarily informed by the medical diagnoses provided in the descriptions of subjects, in identifying types of trajectories.

As a result, a common recommendation in such reviews might be a call for operational definitions and measures of trajectory. Definition has already begun in the works referenced below. However, measurement for research and clinical uses is in its infancy and is not likely to be well developed for some time.

In the meantime, the development of knowledge about chronicity would be enhanced if researchers considered trajectories in their sampling designs. Trajectory information could be included in descriptions of intake protocols, measures, findings, and discussions in research reports.

Early work on trajectories viewed them primarily from a professional, biomedical perspective. Later work has taken the perspective of the individual and the caregiver, in which psychosocial issues come to the fore. Other work on professional-client relationships has found that these two perspectives differ. This suggests that descriptions of subjects could include illness trajectories from more than one perspective – from those of the individual, the caregivers or other family members, or the health-care professionals. How often do researchers ask their subjects to give their views on the course of their condition or trajectory? I suspect we will be in for some surprises.

The concepts of trajectory and transferability hold promise for the enhancement of nursing knowledge about chronicity. I eagerly await the next generation of chronicity research.

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Le point : La chronicité

ÉDITORIAL INVITÉ

Trajectoires et transférabilité : l'étoffement des connaissances infirmières sur la chronicité

Sharon Ogden Burke

Le premier numéro de la *Revue canadienne de recherche en sciences infirmières* consacré à la chronicité reconnaît qu'il y a une réorientation de la production de connaissances infirmières à partir de modèles bio-médicaux et pathologiques (exemplifiés par « un patient diabétique ») au profit de modèles psychosociaux et éducatifs (exemplifiés par « une personne souffrant de diabète » ou plus généralement par « une personne souffrant d'une maladie chronique »). Derrière cette réorientation se cache une thèse générique de la chronicité qui part du principe que les personnes appartenant à des centaines de groupes de diagnostic médical ont davantage de problèmes psychosociaux en commun qu'ils n'en ont de dissemblables ou à base biomédicale (Perrin et al., 1993). Cette réorientation reflète l'importance relative de l'effet de la maladie sur le sujet par opposition à la maladie seule. Par exemple, l'article de Magyary et Brandt examine les enfants et leur famille tandis qu'ils font face à des maladies chroniques dans cette optique générique.

Cette réorientation vers des thèses génériques de la chronicité n'est pas absolue vu que pratiquement tous les chercheurs en sciences infirmières continuent de rendre compte des catégories pathologiques de leurs sujets tout en concevant leurs recherches et en discutant de leurs résultats en vue de les généraliser à une population plus nombreuse de personnes atteintes des mêmes maladies chroniques. Cela reflète le fait qu'une thèse générique est peut-être trop simpliste et que l'abandon des catégorisations médicales est sans doute prématuré. La généralisation des problèmes de chronicité serait sans doute bien servie par la notion

plus pluridimensionnelle de trajectoire pathologique. Par exemple, Ellerton, Stewart, Ritchie et Hirth ont échantillonné des enfants ayant fait l'objet de trois types de diagnostic médical dans l'intention d'échantillonner une gamme de trajectoires pathologiques.

Le concept de trajectoire pathologique chronique englobe des notions comme l'évolution à court et à long terme, la stabilité relative et le degré d'incertitude qui entourent l'évolution de la maladie. Divers groupements de trajectoires ont été proposés qui englobent les trajectoires progressives, constantes, récidivantes et épisodiques (Rolland, 1987 ; White et Lubkin, 1995 ; Wong, 1993).

Deux promesses d'étoffement des connaissances en sciences infirmières sont implicites dans le concept de trajectoire. Premièrement, les trajectoires offrent un moyen de regrouper une myriade de maladies chroniques dans un ensemble plus restreint de trajectoires. C'est ainsi que nous n'aurons plus besoin de répéter la même étude pour chaque population ayant fait l'objet d'un diagnostic médical avant d'utiliser les résultats descriptifs de personnes ayant suivi des trajectoires semblables. Les recherches de Hernandez sur cette question ont été faites auprès de diabétiques. On peut se demander si ses conclusions présentent de l'intérêt pour les personnes suivant des trajectoires semblables, par exemple des personnes atteintes de néphropathie.

La deuxième promesse implicite est que des trajectoires analogues peuvent avoir des ensembles communs de diagnostics et d'interventions infirmières. Voilà une notion attrayante qui, si elle se vérifiait, pourrait permettre aux recherches expérimentales faites sur un groupe de personnes ayant fait l'objet d'un diagnostic médical d'avoir une certaine utilité pour des sujets ayant fait l'objet d'autres diagnostics dans la mesure où ils partagent une trajectoire semblable.

Les chercheurs et les infirmières praticiennes empiriques hésitent à faire ce genre de saut logique par crainte de surgénéraliser. Derrière cette hésitation, on perçoit l'influence de la thèse positiviste logique qui met en garde contre la généralisation des diagnostics médicaux. Rigoureusement appliquée aux recherches menées auprès de personnes souffrant d'une maladie chronique, cela signifie que l'applicabilité clinique directe des conclusions n'est possible qu'après que des recherches expérimentales ont démontré les rapports de cause à effet dans des échantillons sélectionnés au hasard dans des populations bien définies. Énoncé en termes aussi sentis, peu de gens acceptent ce point de vue limité. De plus, la logistique, le temps et les dépenses de répétition de chaque étude menée auprès de personnes appartenant à des centaines d'autres groupes diagnostiques ont quelque chose d'intimi-

dant. Mais surtout, le recours exclusif à cette approche biaisera et limitera la production de connaissances en limitant l'étude aux groupes dont les effectifs sont suffisamment nombreux. Les protocoles d'échantillonnage reposant sur des principes positivistes logiques excluent généralement les personnes qui ont fait l'objet d'un diagnostic médical moins courant ainsi que celles qui souffrent de problèmes multiples, comme celles qui souffrent de problèmes de santé mentale ou d'apprentissage connexes. Cela provoque un nouveau problème de généralisation car la véritable population de personnes atteintes d'une maladie chronique ne peut jamais être échantillonnée en respectant rigoureusement ce point de vue.

Une autre façon d'envisager la thèse de la généralisation positiviste logique est la transférabilité de Lincoln et Guba (1985). La transférabilité des résultats de la recherche à la pratique clinique est jugée par l'utilisateur des conclusions en fonction de la concordance qu'il y a entre l'échantillon et les conclusions d'une part et les clients du praticien de l'autre. Si l'on prend pour guide la transférabilité plutôt que la généralisabilité, les trajectoires des maladies chroniques promettent de générer de nouvelles connaissances.

Il est tentant d'imaginer que la transmission des connaissances infirmières fondées sur la recherche est possible pour les personnes suivant des trajectoires semblables, mais dont les diagnostics médicaux diffèrent. Pourquoi dès lors la trajectoire n'a-t-elle pas remplacé le diagnostic médical pour identifier les populations pour nos recherches infirmières. Je soupçonne que la raison principale a trait à la façon dont nous recrutons généralement des sujets dans un système dont l'orientation est essentiellement biomédicale.

Au-delà de la logistique du recrutement, il y a des mises en garde sur la transférabilité des résultats de la recherche en fonction des diagnostics médicaux mais dans les limites de certaines trajectoires. L'âge, le stade ou la phase de la maladie et la nature des tâches et des stress courants risquent d'entraver l'applicabilité du construit de transférabilité.

L'âge et le stade de développement d'une personne souffrant d'une maladie chronique et sans doute aussi le membre de la famille qui en prend soin devraient exercer une influence sur la notion de trajectoire. Il n'est pas logique d'appliquer la notion de trajectoire à de très jeunes enfants ou à ceux qui ne peuvent prévoir l'avenir. L'idée que les parents se font des trajectoires de leur enfant peut parfois être plus utile que celle de leur enfant.

Il semble logique d'imaginer que l'idée que le client se fait de la trajectoire de son état est d'autant plus intéressante pour les recherches infirmières que ses tâches ou stress courants sont de nature psychosociale. Les diagnostics infirmiers à dominante psychosociale sont sans doute plus faciles à regrouper sous des trajectoires pathologiques que les diagnostics infirmiers à dominante pathophysiologique. Il s'ensuit qu'un cadre de trajectoire pourrait être particulièrement bien adapté aux interventions infirmières de type psychosocial.

Durant les phases aiguës de la maladie, lorsque les problèmes pathophysiologiques revêtent une importance cruciale, un cadre de trajectoire pathologique pourrait ne pas être aussi intéressant pour nos recherches ou notre pratique. Il se peut que les trajectoires entrent en jeu durant le diagnostic préliminaire ou les accès aigus pour deux raisons. Premièrement, les problèmes pathophysiologiques revêtent une suprême importance. Deuxièmement, la trajectoire est un construit cognitif qu'une personne met du temps à élaborer et à mettre en jeu. C'est ainsi qu'au cours des premières phases de la prise de conscience d'un état chronique et de la découverte de son diagnostic et de son traitement, les cadres biomédicaux pourraient se situer à l'avant-scène. Toutefois, dès lors que le « long parcours » (Rolland, 1987) de l'adaptation à cet état devient la question primordiale, les trajectoires peuvent alors présenter plus d'utilité.

D'une certaine façon, nos cadres conceptuels sur la mort et l'agonie peuvent être perçus comme une phase des trajectoires des maladies chroniques, même s'ils n'ont pas toujours été perçus sous cet angle. Si on les considère comme faisant partie de la trajectoire d'une personne, les phases finales des trajectoires pathologiques sont très bien décrites par rapport au long parcours d'adaptation à un état pathologique chronique.

Les prochaines mesures à prendre pour étoffer les connaissances infirmières sur la chronicité consisteront à faire la synthèse des rapports de recherche, des définitions et des mesures des trajectoires et à utiliser le concept de trajectoire pour éclairer la sélection des sujets. Je suppose qu'il y a des thèmes communs que l'on pourrait démêler de la recherche existante par des examens systémiques et par la synthèse des conclusions sur les personnes aux trajectoires pathologiques semblables. Ces examens systématiques pâtiront d'une disette d'informations sur les trajectoires des sujets et ils utiliseront la spéculation, essentiellement éclairée par les diagnostics médicaux figurant dans les descriptions des sujets afin d'identifier les types de trajectoires.

Il se pourrait donc qu'une recommandation commune à ces examens soit un appel à des définitions opérationnelles et à des mesures de trajectoire. Ces définitions ont commencé dans les travaux auxquels nous faisons allusion dans le texte. Cependant, la mesure des recherches et des usages cliniques n'en est qu'à ses premiers balbutiements et ne sera sans doute pas bien développée avant quelque temps.

En attendant, si les chercheurs voulaient bien réfléchir aux trajectoires dans leurs plans d'échantillonnage, cela aiderait à l'étoffement des connaissances sur la chronicité. Des données sur les trajectoires pourraient figurer dans les descriptions des protocoles de prise en charge, dans les mesures, les résultats et les analyses des rapports de recherche.

Les premières recherches sur les trajectoires les considéraient avant tout dans une optique professionnelle et biomédicale. Les recherches plus récentes s'intéressent plus au point de vue de l'individu et du pourvoyeur de soins, là où les questions psychosociales se situent à l'avant-scène. Il serait conforme à d'autres recherches sur les relations professionnels-clients de constater une différence entre ces points de vue. À l'avenir, les descriptions des sujets pourront inclure des trajectoires pathologiques vues sous plus d'un angle, celui des individus, des pourvoyeurs de soins ou d'autres membres de la famille ou enfin des professionnels de la santé. Avec quelle fréquence les chercheurs demandent-ils aux sujets d'exprimer leur point de vue sur l'évolution de leur état ou leur trajectoire. Je crains que nous ne soyons surpris par la réponse à cette question.

Les notions de trajectoire et de transférabilité promettent de contribuer à l'étoffement des connaissances infirmières sur la chronicité. J'attends avec impatience la génération suivante de recherches sur la chronicité.

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Social Support in Children with a Chronic Condition

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La conception descriptive exploratoire de la présente étude a permis à celle-ci de décrire le soutien social aux enfants atteints de maladie chronique et la façon dont les enfants utilisent ce soutien social pour faire face aux exigences de la vie quotidienne et à celles qui sont liées à leur maladie. Parmi les 62 participants d'âge scolaire, on comptait 16 enfants diabétiques, 16 atteints de fibrose kystique, 15 souffrant de spina-bifida et 15 qui n'étaient pas atteints de maladie chronique. On a recueilli des données sur leurs réseaux de soutien social, les diverses fonctions du soutien qu'offraient les réseaux et leur satisfaction par rapport à ce soutien. Les enfants ont également décrit le soutien social qu'ils recevaient et la façon dont ils l'utilisaient comme stratégie d'adaptation à des situations stressantes particulières. Les enfants sains avaient, globalement, les plus vastes réseaux de soutien et les plus grands réseaux de pairs. Les enfants souffrant de spina-bifida avaient, globalement, les plus petits réseaux et le plus petit nombre de pairs dans leurs réseaux. Les enfants sains mentionnaient en général davantage de soutien que les enfants au sein des divers groupes de maladies. Les enfants sains autant que les enfants atteints de maladie chronique ont précisé que les questions scolaires étaient leur source principale de stress chaque jour. Les enfants souffrant de maladie chronique ont établi les restrictions dues à la maladie comme étant le stress le plus important lié à la maladie. Les enfants atteints de maladie chronique ont rapporté davantage de stress et une plus grande recherche de soutien dans les situations stressantes du quotidien que dans les situations liées directement à la maladie. Les résultats serviront à la conception des futures interventions de soutien social auprès des enfants atteints de maladie chronique.

This study used a descriptive exploratory design to describe social support in children with a chronic condition and how children use social support in coping with everyday demands and demands related to their condition. Participants comprised 62 school-aged children (16 with diabetes, 16 with cystic fibrosis, 15 with spina bifida, and 15 with no chronic illness). Data were collected about their social-support networks, the support functions provided by the networks, and their satisfaction with support. The children also described the social support they received and their use of social support as a coping strategy in specific stressful situations. The healthy children had the largest support networks overall and the largest peer networks. Children with spina bifida had the smallest networks overall and the smallest number of peers in their networks. Healthy children reported more support overall than the children in the illness groups. Both the healthy children and the children with a chronic condition described academic issues as the main source of everyday stress. Children with a chronic condition identified restriction due to illness as the key illness-related stressor. Children with a chronic condition reported more

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stress and more support-seeking in everyday stressful situations than in illness situations. The results will guide the design of a future social-support intervention for children with a chronic condition.

In many ways, life for children with a chronic or handicapping condition is better than it was only a few years ago. Advances in health care have ensured that many children are surviving serious illnesses and living into adulthood (Darrow & Stephens, 1992; Drotar, 1981). Furthermore, the capacity to provide for the needs of even medically fragile children outside hospital has improved. Most children are able to live at home with their families (Horner, Rawlins, & Giles, 1987). The lobbying efforts of families and health professionals have resulted in better school transportation and better accommodation of children with a chronic condition within the school system. Concurrently, however, the impact of chronic childhood conditions is placing demands on children's psychological health, which pose new challenges to families, health-care providers, and researchers.

In Canada, an estimated 500,000 children under the age of 20 years (7.2% of all children) have a chronic condition (Statistics Canada, 1991). Almost half of those conditions are serious enough to limit or prevent the child's participation in home, play, or school activities. Children with a chronic condition are considered to be at risk for behavioural and emotional problems (Cadman, Boyle, Szatmari, & Offord, 1987; Wallander, Varni, Babani, Banis, & Wilcox, 1988). Attempts to offset these risks can place heavy demands on family and community resources. There has been some study of the factors associated with psychological and social outcomes in children with chronic conditions (Dorner, 1975; Perrin, Stein, Walker, & Weitzman, 1993). However, the impact of social support on the lives of these children has only begun to be documented, and little is known about their perceptions and use of social support in managing difficult life situations. The purpose of this study was to describe how school-aged children with a variety of chronic conditions view their sources and types of social support, how they appraise the support they receive from their social network, and how they use social support in coping with the developmental and condition-related stress in their lives.

Literature Review

The Health Activity Limitation Survey in Canadian Children (Statistics Canada, 1991) examined the effect of disability on children's lives. Almost 40% of children aged four to 14 years and 50% of older children with a disability were unable to participate in community recreation

programs because of their condition. Older children identified inadequate finances, facilities, and transportation as reasons for their exclusion from leisure activities. Almost 10% of these children believed they lacked the necessary support of family and friends to participate more fully in community activities.

The Effects of a Chronic Condition on Children's Psychological Health

Children with a chronic condition are at increased risk for psychological adjustment problems such as anxiety, depression, peer-conflict, hyperactivity, and aggression (Cadman et al., 1987; Gortmaker, Walker, & Sobel, 1990; Lavigne & Faier-Routman, 1992). Mothers of children with a chronic condition report poor social competence in their children that interferes with peer relationships (Wallander, Feldman, & Varni, 1989) and results in social isolation (Spirito, DeLawyer, & Stark, 1991).

Social and psychological problems associated with chronic conditions may be attributable to generic issues of chronicity rather than particular dimensions of a condition (Stein & Jessop, 1982; Wallander et al., 1988). For instance, chronic illness in children with functional disability has been associated with higher risk for externalizing disorders (Cadman et al., 1987) and chronic conditions affecting the central nervous system have been associated with the highest risk of all for behavioural and emotional problems (Seidel, Chadwick, & Rutter, 1975). Lavigne and Faier-Routman (1992) conclude that children with chronic conditions, regardless of diagnosis, are at greater risk than healthy children for psychological adjustment problems. In contrast, there is some evidence to suggest that children with a chronic condition do not differ greatly from healthy children in their experience of psychological problems (Breslau, 1985; King, Schultz, Steel, Gilpin, & Cathers, 1993; La Greca, 1990).

Social Support and Stressful Situations Experienced by Children with a Chronic Condition

Many children with severe disability are socially competent despite their high-risk status (Egeland, Carlson, & Sroufe, 1993; Garmezy & Rutter, 1983). In adults, social support has been linked to improved self-esteem and the ability to resist stress (Alloway & Bebbington, 1987; Cohen & Wills, 1985; Gottlieb, 1988; Sarason, Sarason, & Shearin, 1986). In healthy children, social support has been associated with self-worth and emotional function (Dubow, Tisak, Causey, Hyrshko, & Reid, 1991). Support from parents has been positively associated with children's

self-esteem and internal locus of control, while support from peers has been associated with less loneliness and higher levels of social competence (Wolchik, Sandler, & Braver, 1987a). In stressful situations such as parental divorce and school transitions, social support for children and psychological adjustment in children have been positively related (Felner, Ginter, & Primavera, 1982; Wolchik et al., 1987a). The few studies of social support in children with a chronic illness substantiate the power of family and peer networks as predictors of adjustment (Holahan & Moos, 1987; Varni, Setognchi, Rappaport, & Talbot, 1992; Wallander et al., 1989).

Some researchers have found that the most common stressful situations for healthy children are academic challenges, peer relationships, and family events and relationships (Brown, O'Keeffe, Sanders, & Baker, 1986; Cowen & Work, 1988; Puskar & Lamb, 1991). Compass, Malcarne, and Fondacara (1988) found that poor grades and peer conflict to be the most commonly identified daily hassles of school-aged children.

Most of the research with children with chronic conditions has focused on their overall stress (e.g., Thompson & Gustafson, 1996), adjustment in response to having a chronic illness (e.g., Lavigne & Faier-Routman, 1992), or coping with painful medical events (e.g., Peterson, Harbeck, Chaney, Farmer, & Thomas, 1990; Ritchie, Caty, Ellerton, & Arklie, 1990) or hospitalizations (e.g., Spirito, Stark, & Tye, 1994). There has been little examination of the stressful events that children with chronic conditions face daily. Gortmaker et al. (1990) and Perrin, Ramsey, and Sandler (1987) point out that children with a chronic condition must also cope with their own reactions to their condition and the reactions of family members and friends. Additional sources of stress may include barriers to their attempts to gain independence and autonomy, limited social opportunities, teasing, restrictions on activity, uncertain employment prospects, medical interventions, and the demands of care (Eiser, 1990; Harper, 1991; Vessey, Swanson, & Hagedorn, 1995).

Bull and Drotar (1991) found that seven- to 17-year-olds with cancer in remission reported having to deal with both general life stressors and cancer-related stress, although they cited general life stressors much more frequently (85.6%) than illness-related stressful situations. The general stressors related to school (23.6%), family (23.6%), and peers (19.3%). The illness-related stressors were restriction due to illness (29.6%), treatment (22.2%), and others (22.2%).

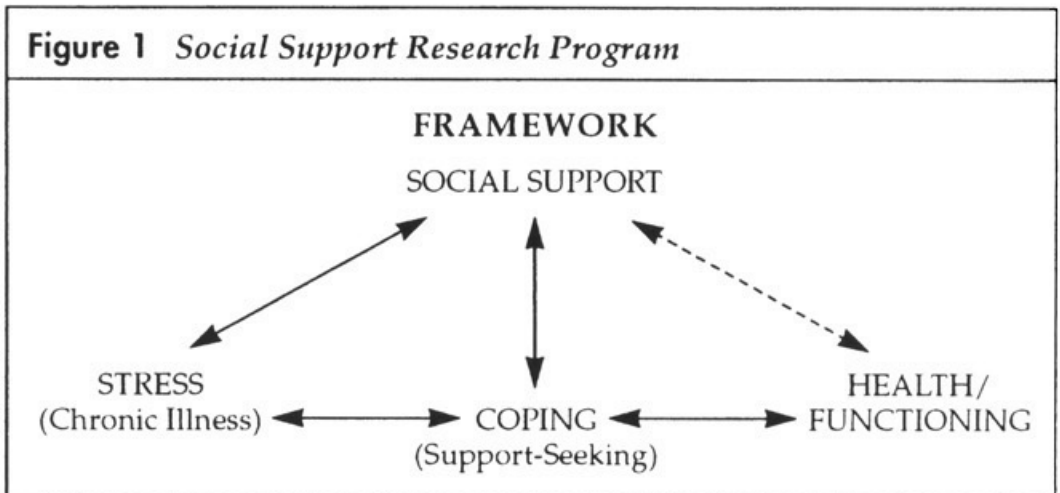
There has been little examination, however, of how stressful situations differ for children with and without a chronic condition, what support they receive for these stressors, and how they view support from their social network. Furthermore, satisfaction of chronically ill children with their support systems has not been studied. Finally, although these children must adjust to a variety of stressful situations, and although social support can help them cope with these situations, little is known about their use of social support, the factors that influence such use, or whether their use of social support as a coping strategy changes with development.

In summary, a large body of literature documents the positive effects of social support on mental and physical health in adults. Family members, adults from outside the family, and peers have been shown to provide complementary support in helping children achieve personal autonomy. Little is known, however, about how children with a chronic condition assess stressful situations associated with daily living and those related to their illness, how children use social support in managing those situations, and the types, sources, and appraisal of support from the perspective of the child.

Conceptual Framework

This study is part of a social-support research program that explores social support and its connections to stress, coping, and health outcomes. Social support is defined here as *interactions with family, friends, peers, and health professionals that communicate information, esteem, aid, or emotional help* (Stewart, 1993). Thus the functions of support are emotional, instrumental (practical), informational, and affirmational (House, Kessler, & Herzog, 1990). These types of support should be specific to stressors encountered (Cutrona, 1990). Furthermore, specific types of support are most helpful when they are provided by specific sources (Dakof & Taylor, 1990). Therefore, the types of support the children received from particular people in the context of specific stressful situations were measured. Support through the network may have negative as well as positive effects (Brenner, Norwell, & Limacher, 1989). Indeed, most social relationships have both supportive and stressful elements (Rook, 1990). Because negative elements may influence health more powerfully than positive ones (House, Umberson, & Landis, 1988; Rook), we assessed the supportive and nonsupportive features of children's interactions and relationships, in addition to the sources and types of support they receive.

As indicated by the two-way arrow in Figure 1, stress and social support have a reciprocal relationship. Conflicted interactions, miscarried helping, and inadequate support can be stressful (Buunk & Hoorens, 1992), as reflected in the arrow from support to stress. Conversely, support can mediate or moderate the impact of stressful situations on health and functioning (Quittner, Glueckouf, & Jackson, 1990).



Social support is conceptualized as a coping resource or coping assistance (Thoits, 1986). As illustrated by the arrow from social support to coping, supportive persons, in order to deal with stressful encounters, can alter stress appraisal, sustain coping efforts, influence choice of coping strategies, and augment coping resources. Finally, perceived availability of social support has been linked to coping effectiveness (Bennett, 1993). Conversely, the arrow from coping to support indicates that the ways in which a person copes provide important clues to potential supporters about whether support is needed and, if it is, the types of support that are needed (Silver, Wortman, & Crofton, 1990). People who use avoidance and distancing tend to have fewer support resources, while support-seeking has been linked to greater provision of support (Dunkel-Schetter & Skokan, 1990). Consequently, children's use of social support as a coping strategy was measured.

The two-way arrow between social support and health depicts a bi-directional relationship (not assessed in this study). The arrow from support to health indicates that integration in a social network, and the ability to draw support resources from the network, can maintain health and facilitate physical recovery (Bloom, 1990; Kaplan & Toshima, 1990). The arrow from health to social support illustrates how health and illness affect availability and quality of social support. The continued need for social support in chronic stressful situations such as illness

can deplete the support (Stewart, 1993) received by children with chronic conditions.

Method

The study used an exploratory cross-sectional, between-groups design to (1) describe and compare the sources, functions, and appraisal of support in children with and without a chronic condition; (2) identify the factors that influence their experiences with support; and (3) describe their use of social support in coping with everyday and condition-related situations, and their satisfaction with support received in those situations.

Sample

The study sample was 62 children between the ages of eight and 16 years. The small sample size limits the power of the study. Detection of a medium effect size at power = .80, $\alpha = .05$ would require a sample of 180 (Cohen, 1992). Data were collected during interviews with 47 children who had diabetes ($n = 16$), cystic fibrosis ($n = 16$), or spina bifida ($n = 15$) and with 15 children who did not have a chronic condition.

The children were recruited either through letters to their mothers, who had participated in an earlier study (Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994), or through contact by the hospital clinic staff. The conditions were selected for their representativeness of differences in treatments, restrictions in lifestyle and mobility, and visibility. The children without a chronic condition were nominated by mothers of participants in the three diagnostic groups from among friends of a sibling of the child with a chronic condition. Friends of siblings were recruited because of the possibility that friends of the children with a chronic condition would differ, in some way, in their support from children in the general population.

All of the children lived at home with their parent(s) and attended school. Thirty-two of the children were between 8 and 12 years old and 30 were between 13 and 17 years old. The average age was 12.6 years ($SD = 2.6$). There were 32 girls and 28 boys. There were no differences among the children in the four groups by gender or age group.

Data Collection

Each child participated in an audiotaped interview conducted by research assistants trained in interviewing techniques. The interview

lasted approximately one hour and took place in the child's home. In the first part of the interview, the child responded to the Children's Inventory of Social Support (CISS) (Wolchik et al., 1987a), which elicits children's general perceptions of sources and types of their social support and their satisfaction with those sources of support.

Many studies of social support have been criticized for their sole reliance on the structural nature of children's relationships and global assessments of support. Therefore, we also asked about supportive and non-supportive interactions and patterns of support during specific stressful situations. We used an investigator-developed narrative interview guide focusing on the children's experience of stressful situations and their use of social support in those situations. First, the child was asked to recall and describe a specific "everyday" event of the past two months that had been stressful. The child then rated the stressfulness of that situation on a 10 cm visual analogue scale. Then the interviewer used probe questions to elicit what the child did to manage the situation, who helped him or her, and what that person said or did that was helpful or not helpful. Finally, the child responded on a five-point Likert scale to the seven "Seeking Support" items from the Self-Report Coping Scale (SRCS) (Causey & Dubow, 1992) in relation to the event they described in the narrative part of the interview. The children in the chronic-condition groups repeated the second part of the interview process in relation to a specific stressful event related to the condition. The interview guide was piloted with four children under 12 years – two with a chronic condition and two without. No changes were made to the interview format as a result of the pilot.

Approval for the study was obtained from the Dalhousie University Faculty of Health Professions and the ethical review boards of the Izaak Walton Killam Children's Hospital and the Grace Health Centre. Children under the age of 12 verbally consented to participate and those 12 and over gave written consent. Parents provided written authorization for their child's participation.

Instruments

The Children's Inventory of Social Support (Wolchik, Sandler, & Braver, 1987b) assesses the child's perception of the source, amount, and type of social support and satisfaction with support received within and outside the family. The interviewer begins by asking the child to select from a list the people (parent, friend, teacher, etc.) to whom the child goes for help or to talk about something (i.e., the source of support). Next, the interviewer explores each of five support func-

tions (advice/information, goods/services, emotional, positive feedback, and recreation/play [added for its relevance in childhood]) by briefly describing each type of support and asking the child to name all the people in the family and outside the family who provided this kind of support in the last two months. The child also identifies the people who have made him/her feel sad, angry, or bad, and rates his/her satisfaction with each support function provided by family members and others on a 10 cm visual analogue scale (support appraisal). Internal consistency reliabilities between .79 and .90 and test-retest reliabilities between .52 and .85 have been reported for the instrument (Wolchik, Ruehlman, Braver, & Sandler, 1989). In a study of children between the ages of eight and 15 years with divorced parents (Wolchik et al., 1987b), which used the CISS, high levels of support from family adults were found to be negatively related to adjustment problems, and peer support was positively associated with social competence.

The Self-Report Coping Scale (Causey & DuBow, 1992) is a 35-item instrument that measures five dimensions of coping (seeking social support, self-reliance/problem-solving, distancing, internalizing, externalizing) in children eight to 16 years of age. The child responds on a five-point Likert scale to a lead question reflecting specific daily stressors. For this study, we used only the "Seeking Social Support" subscale. Internal consistencies and test-retest reliabilities of the seven-item "Seeking Support" subscale of the SRSC range from .60 to .80. In the present study, Cronbach's alpha levels for the everyday stressful situation and the condition-related situation for the "Seeking Support" subscale were .71 and .76, respectively.

Data Analysis

We scored the instruments according to their developers' instructions (the "Seeking Social Support" scale was scored as the total of the Likert responses for each of the seven items [possible range = 7 - 35]), and calculated descriptive statistics for the demographic variables and for the size and functions of the children's support networks, their appraisal of support, and their use of social support as a coping strategy. We conducted one-way ANOVAs to explore the relationships between the study variables and the factors of age group, gender, and study group. Post-hoc analyses were done using Tukey's B multiple-range test to examine where the differences lay. T-tests were used to examine, by age group and gender, differences in number of support functions and appraisal of support. Chi square was used to determine differences in type of helpers identified in different types of stressful situations.

Two of the investigators conducted a content analysis of the children's responses to the narrative interview questions about type of stressful situation, type of helper, type of support, and appraisal of support. The child's complete response to each interview question constituted a unit of analysis and was coded according to a defined category system. The investigators coded the responses independently and achieved consensus in all but five responses. Those five responses were discarded from the data set.

Results

Sources, Functions, and Appraisal of Support (CISS)

The children reported an overall average of 21.3 supporters ($SD = 10.1$) in their networks. Peers formed the largest component of the networks for children in all groups. The composition of the major components of the networks is presented in Table 1. The social networks ranged in size from 26.5 ($SD = 10.3$) persons for the healthy children, to 15.9 ($SD = 9.2$) persons for the children with spina bifida. The scoring of the CISS required that people whom the children identified as providing negative support were not included in the support networks. Typically these negative supporters were siblings and classmates. The number of support functions (i.e., the total number of people providing each type of support – play, advice, goods/services, emotional, positive feedback) reported by the children ranged from a high of 61 ($SD = 26.5$) for the children without a chronic condition, to 33 ($SD = 21.0$) for the children with spina bifida. Overall, the children indicated that they had high levels of satisfaction with their support ($M = 8.5$, $SD = 1.1$).

Factors Influencing Support

Sources of Social Support (CISS). There was a significant between-group difference in the size of support networks ($F(3, 58) = 3.35$, $p = .02$). The children without a chronic condition had the largest support networks (see Table 2), and the post-hoc analysis showed the most significant difference was that between the children without a chronic condition ($M = 26.5$) and the children with spina bifida ($M = 15.9$). There was also a significant between-group difference in size of peer network ($F(3, 58) = 6.39$, $p = .001$). Once again, the children with spina bifida had the smallest peer networks ($M = 3.4$, $SD = 2.4$) – significantly smaller than those of the children without a chronic condition ($M = 11.4$, $SD = 7.3$). There were no differences in network size by age group or gender.

Table 1 *Composition of Social Networks by Type of Supporter*

Type of Supporter	M	Network Size	
		SD	Range
Family Adults	5.7	2.2	2-11
Non-Family Adults	6.4	4.9	1-22
Peers	7.1	5.7	0-28

Table 2 *Overall Network Size by Study Group*

Study Group	M	Network Size	
		SD	Range
Children with Diabetes	19.5	7.4	11-43
Children with Cystic Fibrosis	23.4	7.7	11-37
Children with Spina Bifida	15.9	9.2	4-40
Children without a Chronic Condition	26.5	10.3	11-56*

*($F(3, 58) = 3.35, p = .02$) Children without a Chronic Condition > Children with Spina Bifida

Table 3 *Number of Support Functions by Study Group*

Study Group	M	Number of Support Functions	
		SD	Range
Children with Diabetes	42.5	11.7	17- 57
Children with Cystic Fibrosis	51.2	26.9	28-133
Children with Spina Bifida	33.3	21.0	10- 81
Children without a Chronic Condition	61.8	26.5	26-113*

*($F(3, 58) = 4.49, p = .006$) Children without a Chronic Condition > Children with Spina Bifida

Support Functions (CISS). There were between-group differences in the number of support functions (play, advice, goods/services, emotional, positive feedback) reported ($F(3, 58) = 4.49, p = .006$) (see Table 3). Post-hoc analysis revealed that the children without a chronic illness reported significantly more support overall than the children in the spina bifida group. While there were no differences in number of family-support functions by study group, the children without a chronic illness and the children with cystic fibrosis reported more non-family support than the children with diabetes and spina bifida ($F(3, 58) = 4.98, p = .003$). The children without a chronic condition also reported more support functions from peers than the children in any of the diagnostic groups ($F(3, 58) = 9.93, p = .000$).

The children without a chronic condition reported more providers of all types of support: play ($F(3, 57) = 6.17, p = .001$), information ($F(3, 58) = 4.48, p = .006$), goods ($F(3, 58) = 2.82, p = .04$), emotional support ($F(3, 58) = 2.62, p = .05$), and positive feedback ($F(3, 58) = 3.24, p = .02$). The children with spina bifida had significantly smaller networks (i.e., fewer sources of support), for every type of support, than children in any of the other groups.

The number of overall support functions did not differ by gender. Overall, children over 12 years reported more support functions than the younger children ($t(60) = -2.29, p = .02$, two-tailed). Older children also reported more informational support ($t(60) = -2.27, p = .02$, two-tailed).

Appraisal of Support (CISS). Scores for support satisfaction averaged 8.5 ($SD = 1.1$) on a 10-point scale. There were no differences in satisfaction with support overall, or with support from family or non-family, between the healthy children and those in any of the diagnostic groups. Older children were less satisfied with their support than were younger children ($t(60) = 2.22, p = .03$, 2-tailed). In the diabetes group, the girls were more satisfied than the boys ($t(14) = -2.60, p = .02$, 2-tailed).

Stressful Situations and Related Use of Support (Interview Guide)

The majority of the children responded tersely to the interview questions; only the older girls gave full descriptions of the stressful situations in their lives and the pertinent support rendered by their networks.

Across all groups, children described major everyday stressful events as including academic issues (30%), such as problems with homework and struggles with parents over completing assignments, and peer relationships (29%), such as arguments with and about friends. Other stressful events included differences with siblings (14%), teasing (13%), and chores (5%). There was more consistency in the children's descriptions of stressful events related to their chronic condition than in their descriptions of everyday situations: nearly half (47%) described stressful events related to restrictions attributable to their condition, followed by situations related to treatments (25%), clinic visits (18%), and hospitalization (9%).

Twelve of the children with spina bifida had mobility problems and all but two used a wheelchair. An adolescent girl who used a wheel-

chair shared the frustration associated with her immobility and a fantasy about dancing: "I would like to be able to dance – and I can, sort of. But I wouldn't – not in front of anybody. So I just dance in my head." The children's narratives reflected lives of loneliness and physical and social isolation. Most had few close friends. Almost all of the children with spina bifida described struggles to join peer activities. One child talked about the difficulty of manoeuvring a wheelchair through snow to be with friends. Another described injuries sustained trying to participate in a football game. Many children described their frustration at physical barriers such as steps and inclines that led to their exclusion from outings with other children.

During the interviews, the children rated the stressfulness of the two types of stressful situations. The children with a chronic condition reported higher stress levels in everyday situations ($M = 7.92$, $SD = 1.9$) than in condition-related situations ($M = 6.66$, $SD = 2.7$) ($t(44) = 2.96$, $p = .02$, two-tailed). There were no between-group differences in stress ratings for everyday situations. Stress scores did not differ by age group or gender.

Support Received in Stressful Situations (Interview Guide)

When the children with a chronic condition were asked who helped them manage stressful situations, they identified family members as major supporters in both condition-related and everyday situations. The children without a chronic condition reported that they relied equally on family and friends for support. Children with a chronic condition reported receiving help from non-family members, including peers, in everyday situations more often than in illness-related stressful situations. In non-illness situations, they described receiving advice, material support, and emotional support with equal frequency (31%). In condition-related situations, they described more than a third of their support as emotional (36.2%), followed by material goods (practical support) (31.8%) and advice (informational support) (16.4%).

Children in all the study groups reported being very satisfied with the help they received. The mean rating for satisfaction with support for children without a chronic illness was 8.04. The average satisfaction rating for children with a chronic condition was greater than 8.5 for both condition-related and everyday stressful situations. When the children were asked to describe what was helpful or not helpful in stressful situations, most did not describe interactions that were non-supportive.

Support-Seeking as a Coping Strategy (SRCS)

Total seeking-support scores (out of a possible score of 35) were modes for both condition-related situations ($M = 20.3$, $SD = 5.28$) and everyday situations ($M = 18.2$, $SD = 5.6$). The children with a chronic condition used more support-seeking in everyday situations than in illness situations ($t(42) = -3.03$, $p = .004$, two-tailed). No differences in support-seeking scores were found for everyday stressful situations between the children with a chronic condition and those without a chronic condition.

Summary

The study revealed that children in all the study groups considered family members to be major sources of support. The healthy children reported the largest social networks, the largest number of peer supporters, and the largest amount of support. Children with spina bifida had smaller networks, for every type of support, than the healthy children and the children in the other illness groups, and they reported less support from non-family members, including peers. Older children reported more support than younger children, but less satisfaction with their support. Both the healthy children and the children with a chronic condition described academic and peer issues as major sources of everyday stress; restrictions due to illness accounted for most of the illness-related stress. The children with a chronic condition reported more stressfulness in everyday situations and more support-seeking strategies in everyday situations. Family members provided the majority of support in both types of situation.

Discussion

Consistent with other research on support providers (e.g., Dakof & Taylor, 1990), this study reveals that most support was provided to the children with chronic conditions by family members and within close relationships. The healthy children reported more support overall and in particular, stronger peer support, than the children with a chronic condition. This finding is consistent with those of other researchers (Belle, 1989; Lyons, 1989) that children with disabilities have weaker social networks, which can result in loneliness (Taylor, 1988). The significantly smaller networks of the children with spina bifida, particularly networks of peer supporters, may illuminate the social consequences of childhood conditions that limit physical activity and/or are visible.

The children with spina bifida found themselves socially isolated from peers at school because of their limited mobility, and they had few opportunities to interact with other children because most lived in rural communities. The loneliness of emotional isolation (absence of a close emotional-attachment figure) has been distinguished from social isolation (absence of an assessable social network) (Weiss, 1974). These children seemed to experience loneliness from social isolation. Social support can redress different forms of loneliness and isolation (Rook, 1990).

The children with a chronic condition found situations related to everyday life more stressful than situations associated with their condition. These children shared with their healthy peers normal developmental concerns about schoolwork and about social relationships with teachers, peers, and siblings. The everyday stressful situations they identified were the same as those reported by Causey and Dubow (1992) in their study of healthy schoolchildren and by Bull and Drotar (1991) in their study of school-aged children and adolescents in remission from cancer. The findings may demonstrate the essential normality of life for these children despite their chronic condition. Conversely, it may be that a chronic condition has an indirect impact on a child's life; for these children, everyday activities are not really "non-illness" situations. Although the stressful situations in everyday life are the same as those for healthy children, the child with a chronic condition must manage the additional stressful situations associated with the condition.

The children with a chronic condition used support-seeking more as a way of coping with stressful situations in everyday life than in illness-related situations. Support-seeking, as a coping strategy, has been linked to receiving greater social support (Dunkel-Schetter & Skokan, 1990).

The older children reported more overall support than the younger children. The social skills necessary for forming and maintaining relationships (Ford & Procidano, 1990) increase as children develop. However, the older children expressed less satisfaction with their support. This finding is consistent with the challenges of early adolescence, including the acquisition of new cognitive abilities, the transition to junior high school, the need to develop new friends, the decreasing impact of parental attitudes, and the increasing importance of peer influence. For the older children with a chronic condition, these issues were found to be as stressful as those related directly to their illness.

In a study, preceding this present investigation, of the support needs of mothers of children with these three chronic conditions (Stewart et al., 1994), the mothers described extraordinary efforts to provide supportive environments for their children. Yet they worried that life was difficult for their children and that they lacked the support necessary for healthy development. Clearly, parents were the main providers of support for the children with a chronic condition. Regardless of risk conditions for children, such as chronic illness (O'Dougherty & Wright, 1990), the importance of supportive caregiving as a protective factor has been highlighted (Egeland et al., 1993; Rutter, 1990). The results of the study suggest that children recognize and value the support they receive from their families.

Many of the stressors described by the children developed in the context of coping with peer relationships and the social consequences of illness. The expressed needs for peer friendships suggest the value of helping children develop relationships with peers, in which they learn to cooperate, appreciate others' ideas, and develop skills around consensus-building and reciprocity. These experiences were lacking in the lives of the children with spina bifida. In spite of the differences in support for the children with spina bifida, the results suggest that these children were similar to their healthy peers in their assessment of stressors and their need to develop the social skills to cope with both development and their chronic condition. Research has demonstrated that when children with disabilities have friends and are integrated in schools they have improved self-confidence, communication skills, academic performance, participation in social life and extracurricular activities, social skills, and sense of belonging (Bradley, 1994; Giangreco, Dennis, Cloninger, Edelman, & Schattman, 1993).

The findings of this study have implications for the theoretical interpretation of social support, for nursing practice and for intervention research. Conceptually, two sources of support are particularly important from the perspective of children – parents and peers. The children with limited mobility got most of their support from their parents, and they had less support from peers than children without a chronic condition. Furthermore, support was specific to stressful situations, and support-seeking as a coping strategy was used more by the children with a chronic condition in stressful situations, suggesting conceptual links among stress, coping, and support. A key contribution of this investigation to the study of children's social support was its assessment of sources, types, and appraisal of support, and specificity of support for stressful situations from the perspective of the children themselves – rather than from the perspective of parents and teachers.

These results can inform the development of support interventions in nursing practice, and they have helped to shape our thinking around the kind of support intervention that should make up the next phase of this research. The intervention should provide the opportunity for children who are isolated, because of their geographical location and/or their physical status, to interact with other children. The similarity of the issues raised by children across groups suggests that the intervention could include healthy children as well as those with various chronic conditions. The inclusion of young children could provide them the opportunity to develop social skills in a representative peer group before they are confronted with the complex social issues of adolescence.

The protective factor – social support – has been linked to resilience in children with chronic conditions (Brown, Doepke, & Kaslow, 1993). The effects of vulnerability and protective factors in childhood should be considered when strategies are developed to help children manage stressful situations. The results of this study provide a more extensive picture of the pattern of social support and the use of social support as a coping strategy by children with a chronic condition, and suggest that, for some children, there is considerable social isolation that may contribute to the previously reported differences in social competence.

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Integration: The Experience of Living with Insulin Dependent (Type 1) Diabetes Mellitus

Cheri Ann Hernandez

Dans la présente étude théorique à base empirique, c'est à partir de l'analyse d'entrevues et de données écrites de douze adultes diabétiques insulino-dépendants que l'on a examiné ce que signifie vivre avec l'insulino-dépendance. On y décrit la théorie à base empirique de l'intégration : l'intégration de l'être en tant que personne et celle de l'être en tant que diabétique. L'intégration est un processus en trois étapes : le fait d'être diabétique, le point tournant et la connaissance que l'on a de la maladie (science of one). Les gens qui étaient dans la phase de connaissance de la maladie étaient devenus des experts en diabète et bien qu'ils n'adhéraient pas au régime de vie que préconisaient les spécialistes de la santé, ils contrôlaient bien leur glycémie. Chacun avait mis en place un style de vie qui facilitait ou entravait le processus d'intégration. La présente théorie de l'intégration indique la nécessité de changements importants dans la relation malade-infirmière, et dans l'information que l'on peut donner sur le diabète.

In this grounded theory study, the experience of living with insulin dependent diabetes emerged through analysis of interview and written data from 12 adults with the condition. The grounded theory of integration – the integration of the personal and the diabetic selves – that emerged is described. Integration is a three-phase process: having diabetes, the turning point, and the science of one. Those in the science of one phase had become experts in their diabetes and, although they did not adhere to the regimen prescribed by health professionals, they were in good glycemic control. Each person developed lifeways that facilitated or inhibited the integration process. This theory of integration suggests a need for significant changes in client-nurse relationships and diabetes education.

Diabetes mellitus is a chronic disease that results from an absolute or relative lack of insulin or its physiologic function (Cahill, 1985). The earliest known descriptions of diabetes date from about 1500 B.C. (Cahill), but the focus on treatment did not begin until the 1900s (Etzwiler, 1984). Current treatment involves educating clients about diabetes, prescribing a treatment regimen (diabetes regimen), and motivating clients to adhere to this regimen, because health professionals believe adherence leads to glycemic control (Hernandez, 1994), which is, in turn, necessary

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for the prevention of complications (Diabetes Control & Complications Trial Research Group, 1993).

Previous research has focused on predicting or promoting adherence through the use of a variety of theories, strategies, and techniques recommended by health professionals. In contrast, this grounded theory study describes the participants' view of diabetes – the experience of living with insulin dependent diabetes mellitus (IDDM) and the metaphors of integration that characterize this phenomenon.

Background

Diabetes affects about 4% to 6% of the population in Canada (Expert Committee of the Canadian Diabetes Advisory Board, 1992). Approximately 16 million people in the United States have diabetes (American Diabetes Association, 1996).

The impact of diabetes on the individual is significant, because it causes major disruptions in lifestyle and functional health and results in increased morbidity and mortality. In current approaches to treatment, designed to counteract these potential consequences, the emphasis is placed on educating the person with diabetes about the disease and the diabetes regimen it entails. Education programs are designed to help clients normalize blood glucose levels, thereby reducing complications. Metabolic (glycemic) control is considered the ultimate outcome for clients with diabetes (Brown, 1990), but adherence is regarded as an important goal of education programs (Mazze, 1986) because it is believed that adherence to a diabetes regimen is necessary for glycemic control (Alogna, 1980; Becker & Janz, 1985; Cohen, Tripp-Reimer, Smith, Sorofman, & Lively, 1994; Geller & Butler, 1981; Jenny, 1984; Rosenstock, 1985; Tillotson & Smith, 1996). Therefore, much of the diabetes educator's energy is devoted to diabetes control issues – presenting information to clients in a manner that promotes adherence, or structuring the practice situation in a way that facilitates adherence (Hernandez, 1991).

Despite the efforts of educators, adherence has been an elusive goal (Kurtz, 1990; Rosenstock, 1985; Schlenk & Hart, 1984), and investigators have not detected a relationship between adherence to the prescribed regimen and glycemic control (Glasgow, McCaul, & Schafer, 1987; McCaul, Glasgow, & Schafer, 1987; Polly, 1992; Watkins, Williams, Martin, Hogan, & Anderson, 1967; Williams, Martin, Hogan, Watkins, & Ellis, 1967; Wooldridge, Wallston, Graber, Brown, & Davidson, 1992). In addition, the results of diabetes simulation exercises undertaken by

nurses and other health professionals indicate that even they could not adhere to a diabetes regimen, in spite of the short period of the simulation (Warren-Boulton, Auslander, & Gettinger, 1982; Welborn & Duncan, 1980). The inability of the adherence framework to explain the experience of living with diabetes verifies the need for an alternative understanding of what it is to live with diabetes.

Diabetes practitioners have failed to recognize the contradictory role that conventional practice and the diabetes research and theoretical literature have promoted for those with diabetes. On the one hand, educators encourage clients to take charge of their diabetes (Feste, 1992; Funnell et al., 1991); on the other hand, education programs promote acquiescence to the diabetes regimen, the verbal and/or written instructions of the diabetes educator/team. This inconsistency is illustrated in an article in which the purpose of education was identified as the process of enabling clients to make informed choices about their diabetes self-care, but educators were told to measure client adherence to understand their difficulties adhering to the regimen (Anderson, Fitzgerald, & Oh, 1993). It is not known how individuals with diabetes perceive and handle this conflicting role demand. The literature reflects the health professional's view of diabetes. Omitted is a description of what it is to live with diabetes, the perspective uncovered in this research.

When the researcher began this study, there were no reports of investigations into the experience of diabetes from the perspective of the client. A few researchers have begun to focus on selected aspects of diabetes, using in-depth interviews with clients to obtain information about their perspective. These studies demonstrate how individuals with diabetes perceive the impact of their diabetes (Oram, 1992), how they undertake self-care management decisions (Nichol, 1990; Paterson & Sloan, 1994; Price, 1993), or focus on the problems of living with diabetes (Maclean & Oram, 1988) or its complications (Ternulf Nyhlin, 1990). The literature is devoid of reports on the overall experience of living with diabetes.

The research question of the current study was framed as "What is the experience of living with insulin dependent diabetes as described by adults who have it?" The goal was to generate a theory to account for the pattern of behaviour that is relevant and problematic for those with IDDM. The study began with the interviewing of four participants over a two-year period (Hernandez, 1991), with subsequent theoretical sampling over a three-year period. The educational implications of the findings have been published elsewhere (Hernandez, 1995b).

Method

The method of inquiry was grounded theory methodology (Glaser, 1978, 1992; Glaser & Strauss, 1967; Strauss, 1987), in which the data have been systematically analyzed in such a way that the emerging theory results from the continuous interplay between analysis and data collection (Strauss & Corbin, 1994). Other important features of grounded theory are theoretical sampling, data collection guided by emerging theory, and write-up of theoretical ideas – as they emerge – in memo form. This method was selected because it offers the researcher a fresh perspective of a familiar situation (Stern, 1980). Prior to undertaking this study, the researcher had been involved in diabetes education for 10 years and was entrenched in the adherence framework (the professional view), whereas grounded theory methodology allowed me to view diabetes from the perspective of the person with diabetes. A combination of semi-structured interviews and writing tasks was used to facilitate accuracy and completeness of the interpretations.

Sample

Twelve participants were recruited with the assistance of endocrinologists and nurses and through self-referral. Participants were adults over the age of 21 with IDDM. The first participants, two males and two females, were between the ages of 24 and 39, in good glycemic control as judged by glycated hemoglobin, and not health professionals. Over a three-year period, eight more participants were recruited, the selection of whom was based on emerging theory, which guided the choice of participants to be interviewed next. For example, the first four participants all had good glycemic control; therefore, to determine the impact of level of glycemic control on the emerging theory of integration, the next participant had to be in poor glycemic control; then two health professionals with good glycemic control were recruited; later, two participants over age 50, with diabetes for 35 or more years, were interviewed; finally, three participants from a different geographic location were included in the study.

Procedure

An ethical review of the study was completed by the University of Toronto. The researcher conducted all interviews except those of the last

three participants, who were interviewed by a master's prepared nurse, in another location. The participants were initially contacted by phone and an appointment was made for the first meeting. Each person was seen on three or more occasions. The purpose of the first interview was to ensure that study criteria were met, to explain the purpose of the study, to choose a fictitious name that would be used in all interviews, and to obtain written, informed consent. The fictitious names were chosen by the participants and were used in all audiotapes and written data.

At the second meeting, participants were interviewed for about one and a half hours in their homes. The interviews were audiotaped and transcribed verbatim. Interview questions were open-ended to facilitate elaboration and to capture the participants' experiences and feelings. Twelve open-ended questions were developed for this study and were used only if the participants did not offer any of the desired information. These 12 questions had been reviewed by an experienced grounded theory researcher and revised based on that review. The initial interview question was "I want to get some idea of what the experience of living with diabetes has been like for you, from the beginning and up to the present. Could you talk about that for me?"

At the end of the first interview, the writing tasks (a diabetes paper and a diabetes journal) were described and notebooks were provided. The diabetes paper presented an opportunity for participants to tell their personal stories. No firm guidelines were provided for the paper, but it was designed to gain an understanding of what it is like to have diabetes, from the perspective of the writer. The journal was to be an ongoing record of the participant's thoughts relative to diabetes. Participants were asked to keep this journal for a minimum of three days. The writing tasks were completed by the first four participants but were optional for the subsequent eight, because these tasks were thought to limit the type of participant who could be included in the study. Of the eight, three completed both paper and diary, four handed in the diary only, and the remaining participant performed neither task.

The final interview lasted one to two hours and was held from six months to one year after the initial one. This interview took place after all writing tasks had been handed in and analyzed. Its purpose was to validate the researcher's interpretation of the data or to ask further questions that had been prompted by the data analysis. Additional interviews were held at the request of some participants.

Data Analysis

Data collected through the interviews, diabetes paper, and diabetes journal were analyzed using the constant comparative or grounded theory method (Glaser, 1978, 1992; Glaser & Strauss, 1967; Strauss, 1987). Interview data and written data were constantly compared for similarities and differences and patterns of relationships. Line-by-line scrutiny of the data generated substantive in vivo codes such as "being like others," "being like a regular person," and "not being different," reflecting the substance of what the participants said, often in their exact words. As these codes were sorted and compared, they were clustered into larger categories – for example, the above in vivo codes were collapsed into a category labelled "being normal." This intensive analysis "sparked" many memos. Memos were useful in reducing the number of categories, providing leads as to where to go next with the interviews or the theoretical sampling, and identifying hunches or sources of discord as the theory was developed. They were essential to writing up the findings. As linkages between categories were discovered, they were collapsed into general categories. Three major conceptual categories were identified, which together described the Basic Social Process (BSP). The BSP met the BSP criterion of accounting for the changes and adjustments that occurred over time following diabetes diagnosis.

Results

Integration was the BSP underlying the experience of insulin dependent diabetes: having diabetes, the turning point, and the science of one. This theory of integration will be described and participants' comments will be used to illustrate key aspects.

The experience of living with IDDM was a three-phase process of integration: having diabetes, the turning point, and the science of one. Integration is defined as "an ongoing process in which the two selves (diabetic and personal) more fully merge to create an individual who is healthy, both mentally and physically. This unification of the selves is manifested in the person's ways of thinking, being and acting (including verbalization)" (Hernandez, 1995a, p. 19). The *personal self* is the person as he or she existed prior to the diagnosis of diabetes. The *diabetic self* is the new entity that emerged and had to be contended with upon diagnosis. A metaphoric theme seemed to permeate each story, including the language used to tell the story. These themes were labelled *metaphors of integration*, because they demonstrated the orientation of the participants toward their diabetes and toward life, and

they represented the process of living in which the *diabetic self* and the *personal self* have become integrated. However, those in the having diabetes phase had passive metaphors that reflected minimal integration and hindered the integration process.

Two internal conflicts began in the having diabetes phase: *Who owns diabetes?* and *To tell or not to tell?* These conflicts could be resolved in any of the phases. For those in the having diabetes phase much of the *ownership of diabetes* was still in the domain of the health professionals, but for those in the science of one phase the person with diabetes had taken ownership. In the having diabetes phase, participants focused more on following the rules (diabetes regimen) set by health professionals; failure (inadequate glycemic control) was attributed to their own inability to follow the rules. During the turning point, there was more involvement with the diabetes and with decision-making. In the science of one phase, the individual had taken ownership of the diabetes and the decisions related to all aspects of the disease. Health professionals were used to seek updates about research findings or new products, or to vet ideas. However, the ultimate decisions were made by the individual with diabetes. Mike made the analogy that when you are first diagnosed you become like a child again and want the diabetes educator to tell you what to do. Later, "You go into maturity. You start making the decisions for yourself." Mike believed this transference of ownership should also hold true for children with diabetes, because "even children have a feeling for their own bodies." Sarah's attitude was more poignant, "If I want to ruin my life, I will ruin my life. If I want to make my life be good, I will make it be good."

Deciding *whether to tell* another that one had diabetes was a major source of internal conflict. Resolution can take years, and even those in the science of one phase limit the number of their confidantes based on the perception of a need to know or a threshold of intimacy in a relationship. Telling does not necessarily occur in a verbal exchange, as Bridget demonstrated in one of her journal entries:

I was sitting in class and realized I hadn't taken my insulin. I didn't want to do it there because of who was sitting beside me. I wasn't sure how he would take it if he saw me using my Novo-Pen.

Richard showed that he was comfortable with revealing his diabetes in some situations, and in some ways, but not in others:

I would say that's one area that I have certainly changed. I never used to – I used to try and hide the fact that I was a diabetic. But now whenever I travel with anybody at all, I always make a point of telling him right off the bat, "I am diabetic." It makes so much sense, and yet

before, as I say, I was probably embarrassed and didn't want to talk about it.

I've got a diabetic colleague. He'll sit there in a meeting and just get his pen [insulin injection device] out and roll his sleeve up and do an injection in front of everybody sitting there. No inhibitions at all. I don't feel comfortable doing that.

Phase One: Having Diabetes

The first phase of the theory of integration, *having diabetes*, began with diagnosis. It was characterized by a lack of knowledge or fragmented, unconnected pieces of knowledge. During this phase the person with diabetes may exhibit lack of interest in or denial of the diabetes. Diabetes is frequently relegated to a small corner of one's life. All participants in this phase had poor glycemic control. Integration is minimal in this initial phase.

There are varying degrees of commitment to diabetes management. The major preoccupation is *being normal* – or not different from others – being thought of as normal, and living life as a normal person. During the first interview, Marlene identified 12 things she did that are not required of nondiabetic individuals, but after identifying each she quickly followed up with such statements as "To me it's just like everybody else" or "There's no difference, you know."

During the having diabetes phase, the tendency was to do the necessary self-care tasks and then to get on with life and forget about diabetes for the remainder of the day. The having diabetes phase was found to last for three years or more. Three participants were in this phase after having diabetes for seven years or longer.

One begins to have increased self-awareness of the body in this first phase, but it is a more passive awareness than is characteristic of the later phases. Two passive metaphors seemed to impede movement beyond this initial phase, and also to move the focus to being normal or not different. *Fitting in* was Bridget's concern, and diabetes just did not fit in with her desired lifestyle. This metaphor was clearly identified in her response to the question about where she would ideally like to be on the graph she had drawn of diabetes stability versus diabetes flexibility:

I can still fit with the group per se. The whole fitting in process is very important to me ... acceptance is a very, very high priority.

Kathleen's passive metaphor *going along with* promoted continuation in this phase. Going along with the suggestions or plans of others

characterized Kathleen's relationships in both diabetes-related and other aspects of her life: "I had no idea of the word [diabetes] and so therefore I just simply went along with everything." During her last interview, Kathleen described a recent incident whereby she skipped her breakfast even though she had taken her insulin, because her daughter was in a hurry to leave for their weekend at the cottage. Kathleen decided to go along with this despite the knowledge that to do so would most definitely put her at risk of hypoglycemia. The two passive metaphors *fitting in* and *going along with* were part of being normal; they encouraged the person to continue in this phase and discouraged the transfer of ownership from the health professional to the person with diabetes.

Phase Two: The Turning Point

The first four participants were in the science of one phase, so initial understanding of the turning point phase was based on their memories of this period. Later, Kathleen was recruited. She was at the turning point when first interviewed but had reverted back to the having diabetes phase by the end of the study. Kathleen's experience demonstrates that individuals in the turning point phase can either return to the first phase or go on to the science of one phase.

The having diabetes phase ends when some event breaks through the seeming complacency of this phase. No longer can diabetes be ignored, diminished, or denied. Sometimes the precipitating event was a physiological one such as having several hypoglycemic reactions or an episode of ketoacidosis. With others, it was referral to a diabetes specialist who started making intrusive changes in the regimen or helped the participant gain an increased understanding of their diabetes. At this point, the person with diabetes is forced to reassess and rethink life with diabetes. Diabetes becomes much more of a focus. The result is an interest in learning about diabetes and total involvement with self-care, which brings with it a sense of confidence and power. Individuals who remained in the having diabetes phase described experiencing events that had stimulated others to move into the turning point but that had not promoted a turning point in their situations.

Mike identified his turning point: "The thing that got me really interested...was the fact that I had all these reactions. Because no one, nobody, ever told me anything about reactions." Matthew said,

It was about three years, when I first started to see Dr. A., that I was glad and I began to understand how to keep it [blood glucose] down

as well... But as soon as I started to do that, as soon as I started to take better care of myself, the benefits were obvious.

Kathleen was in the turning point phase for over a year. It was prompted by her agreement to go on an intensive insulin regimen at the request of her endocrinologist. Kathleen found that this regimen made her continually hungry and made her think much more about her diet as well as other aspects of her regimen, such as more frequent blood tests and insulin injections. Later in the study, her youngest daughter moved out. Kathleen had depended on her daughter for assistance during her night-time hypoglycemic reactions. On the researcher's last visit, Kathleen had switched back to her previous insulin regimen because she could not cope with the new regimen. It made her think too much about her diabetes and she was not prepared to make the required changes. Kathleen validated that she was in the having diabetes phase when the researcher showed her the three phases of integration and asked her which phase she was in.

Phase Three: The Science of One

The third phase occurs as a gradual progression out of the turning point. It was termed the *science of one* because it involves the ongoing, incremental process of building a unique, personalized, and exact science of living with diabetes. The focus continues to be on living (psychosocial emphasis), but not to the detriment of the diabetes (physiological status). Participants in this phase were in good glycemic control.

During this phase, individuals develop a deep understanding of their own diabetes. Often, professional advice is found to be unhelpful, inaccurate, or unfeasible, given the real world with its variety of multifaceted situations (Hernandez, 1991). Since there is no recognized source of accurate information, the person with diabetes learns to *tune in* to his or her own body, responding appropriately to body cues and sensations experienced through this heightened sensitivity. Matthew spoke of the *tuning in* process:

You can become very aware of what your body needs and how it works...you know what your body demands at certain times... you become very focused on paying attention to it.

In her diabetes paper, Ahuva provided a clear description of *tuning in*:

When we go for a hike we carry lots of emergency rations and every so often I will stop and get in touch with my body. It is likely to be sending me some little signal and I have to get used to knowing what they are.

This phase involves active self-experimentation in which life and living become a laboratory for the development of a science of one, a way of living with diabetes that allows persons with diabetes to focus on living their lives, rather than on their diabetes. Diabetes becomes an integral part of them, not an external matter to be taken care of perfunctorily before they get on with the business of living. Debbie illustrated:

The injections are nothing to me, to give them is nothing. Because I've done it for quite a long time so I'm used to that. You know, it does become a routine, a part of your life. It becomes, in some way, you. You are it, it is you. You know? You fit – hopefully you can fit it together, your life and the diabetes.

Quotes from Erica's journal and interview show the extent to which integration can occur:

I decide what I'll eat, and in view of this and my blood sugar, I decide about my insulin. This all happens so quickly and so easily/readily I hardly think of it as "thinking" about my diabetes.

Where I'm at in my experience with it [diabetes] now is that I don't probably separate it out as an experience that I define in and of itself. It's just part of my everyday living. It's just integrated into my living. I can't really separate it out right now.

The tuning in process is just one of several *lifeways*, the "characteristic patterns of thought or action used without conscious knowledge" (Hernandez, 1991, p. 99) that facilitate integration of the *diabetic* and *personal* selves during the science of one phase. These strategies could be either physical, emotional, or cognitive, but they all served to promote integration of the two selves. The particular lifeways that characterized any one individual were consistent with his or her *metaphor of integration*. In fact the metaphor of integration acted as an overarching or all-encompassing lifeway, tying all of the lifeways together.

Many used *exercise* as a physical lifeway, for enjoyment, positive feelings, and flexibility in lifestyle, and to lower blood glucose. In Laura's case, exercise was a part of her *personal* self that she enjoyed and wanted to continue; she found it had benefits for her *diabetic* self:

I have very strong feelings about diabetes and exercise. I feel they go hand in hand. I have an exercise bicycle which I ride ten miles a day.... It's kind of my own time to relax and read. I always feel good after exercising. A day does not go by that I haven't ridden my street bicycle or my exercise bicycle. I have always been sports oriented and enjoyed exercising and now I make a point of it.

Constant thinking, a cognitive lifeway, is illustrated by Sandra's comment:

I live with my diabetes and I sort of like having it. I like who I am and I like what I do. And I don't mind it at all, and I do think about diabetes all the time during the day.

The overall result of these lifeways is the melding of the diabetic self and the personal self, so that they become inseparably unified. Living involves a combination of diabetic and personal factors, but these are not separated out in the person's thoughts or actions. Rather, they have been integrated into a new and complex self.

Four metaphors emerged from the data of those in the science of one phase: diabetes as work, learning to live with diabetes, focusing on feelings, and juggling for control. These metaphors appeared to form the overarching lifeway, reflecting the participants' orientation to their diabetes and promoting integration of the personal and the diabetic selves. In some instances these metaphors were reflective of the participants' attitude to life in general, even prior to their diagnosis.

The most common metaphor was *diabetes as work*. Sandra strove to keep her blood sugar in the normal range, although this was hard work because of her diagnosis of brittle diabetes. She calculated her insulin dosage and her diet using subjective and objective sources of information, and she worked in as much physical activity as she wanted. "It's a challenge to work, work with diabetes and find out more about it," Sandra explained. Richard's interviews and journal reflected several types of work: balancing work with his blood glucose, planning work, calculated risk-taking work, exercise work, and collaborative work with his diabetes educators.

Laura's metaphor was *learning to live with diabetes*:

I have my high blood sugars and my lows, but these are part of my being diabetic and I have learned to live with them. It's knowing your body and how it reacts to highs and lows and knowing what to do which I have learned, and to take it all in stride.

Matthew was *focusing on feelings*, both physical and emotional. He commented, "The only yardstick I use to measure my diabetes is really my blood sugar and how I feel, but I tie these two together." A journal excerpt exemplifies this metaphor:

Decided I needed some exercise before going to bed, or b.s. [blood sugar] would be high in the morning... thought that it must look/ seem strange to roommates that I was exercising so late at night, but keeping blood sugar low, at a comfortable level, worth it.

The final metaphor was *juggling for control*. Mike described juggling diabetes factors along with other life factors. However, because these factors cannot be totally separated the juggling is challenging and very difficult: "Normally the things that are a part of diabetes control are controllable. It's the other things that you can't control and when those go wrong that's when the other [diabetes] ones are affected because they are joined in a way."

Because those in the science of one phase had become experts in their own diabetes – by tuning in to their bodies, experimenting, and learning experientially – they were impatient with educators who tried to tell them what they should and should not do. These participants stated that educators who do not have diabetes cannot truly understand what it is like to have it. Participants believed educators should work collaboratively with them, because they have particular knowledge about their own diabetes while health professionals have general, scientific knowledge about diabetes that might not apply in their case. The researcher used the term *collaborative alliance* to describe this desired relationship.

Discussion

The theory of integration represents a view of diabetes that differs from the adherence perspective characteristic of conventional diabetes education and treatment. Integration theory describes the ongoing integration of selected aspects of diabetes and the diabetes regimen into the life and lifestyle of the individual, while maintaining a focus on the art of living. This is accomplished through heightened self-awareness of the body, various lifeways, a deep understanding of one's own diabetes, and taking ownership of one's diabetes. The content and style of living that resulted from this process often deviated substantially from the guidelines, rules, and regulations that would make up the diabetes regimen established by a diabetes educator. Yet diabetes educators would consider those in the science of one phase in "good" glycemic control. This finding is in direct conflict with the conventional belief that adherence is necessary for good control of diabetes (Alogna, 1980; Becker & Janz, 1985; Cohen et al., 1994; Geller & Butler, 1981; Jenny, 1984; Rosenstock, 1985; Tillotson & Smith, 1996).

Research findings consistently note that a client's view of a health issue differs from the prevailing scientific or medical views (Cohen et al., 1994; Corbin & Strauss, 1988; Jeffrey, 1989; Kleinman, 1988; Kleinman, Eisenberg, & Good, 1978; Nichol, 1990; Roberts, 1982). Kleinman and others (Kleinman et al.) differentiate the physician's preoccupation

with the *disease* (focus on biology and psychophysiology) from the patient's concern with *illness* (personal, interpersonal, and cultural reactions to discomfort). Anglo-Canadian and Chinese adults with diabetes stated they were able to obtain help from health professionals with the physical aspects of illness but were alone in dealing with the psychological impact (Anderson, 1990). Corbin and Strauss (p. 169) conclude that the medical focus on adherence is excessively physiological and obscures the complex actions required to meet its prescriptions. Nichol (p. 95) determines that adherence is negative because it encourages obedience to the health professional rather than observation and exploration of personal experience and discovery of alternative practices that could promote individual health. Non-adherence or "cheating" has been viewed as potentially positive, because it involves experiential learning (Maclean & Oram, 1988). In this study, participants in the science of one phase were focused on the psychosocial aspect but not to the detriment of physiological status.

Other researchers have found that chronic illness is not a static event but a continuous trajectory. In research with children and adolescents, Quint (1969) found that diabetes is not an event, but rather a "process of becoming diabetic," of merging role identity. Corbin and Strauss (1988) describe the process of reconstituting identity in which some aspects of the self are retained. They indicate that the chronic illness can be either discounted, kept separate from the rest of the biography (similar to the having diabetes phase in the present study), well integrated, so that the illness and its associated work "is me" (similar to the science of one phase), or somewhere in between.

Strauss and Glaser (1975, p. 58) describe a normalizing strategy – to live as normally as possible despite the chronic illness – as the chief business of the individual who is chronically ill. This responsibility for normalization becomes that of the parents when a child has diabetes (Quint Benoliel, 1975). This normalizing strategy is similar to the focus on being normal that is characteristic of the having diabetes phase of the theory of integration.

Recent qualitative studies of clients with diabetes share some findings with this study. Quint (1969) identified reluctance on the part of subjects to divulge the fact that they had diabetes; she found openness in children but secrecy in adolescents. In contrast, this present study found secrecy to be a reflection not of age but of phase – with increasing openness characterizing later phases of integration. Other researchers studying self-management of diabetes describe a body-listening or

tuning-in process (Price, 1993), self-care decision-making (Paterson & Sloan, 1994), and processes by which clients make changes to a prescribed regimen when it does not work for them (Oram, 1992; Price). Other researchers acknowledge the expertise that clients and families with children develop through experiential or trial-and-error learning (Maclean & Oram, 1988; Paterson & Sloan; Quint), and recommend partnership or collaborative relationships with clients who have diabetes (Paterson & Sloan; Ternulf Nyhlin, 1990) or chronic illness (Thorne & Robinson, 1989).

There are further differences between the findings of the present study and those of other researchers. Quint (1969) found that the physician, not the client, was viewed as the source of expert knowledge, whereas the present study found that in the later phases of the process the client had expert knowledge of his or her particular diabetes.

A well-constructed grounded theory will meet four criteria: fit, work, relevance, and modifiability (Glaser, 1978, 1992; Glaser & Strauss, 1967). The theory of integration has demonstrated *fit* in the eyes of the participants, others with diabetes, and other researchers. This theory *works* because it is able to explain the major variations in those who are living with diabetes. According to Glaser (1992), if a grounded theory both fits and works, then it has achieved *relevance*. The theory of integration was shown to be modifiable as new data presented.

The assumption of common experience of a three-phase process of integration in those with IDDM may not be justified by documenting the integration process in 12 people. However, the trustworthiness of this process is inferred through Lincoln and Guba's (1985) criteria of *credibility* (internal validity), *transferability* (external validity), and *dependability* (reliability). Credibility was promoted through prolonged engagement with participants, triangulation of data-collection methods (interviews, diabetes papers, journals), and member checks (checking data and interpretations with participants). Transferability is ensured when the research provides "the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility" (Lincoln & Guba, p. 316). When these research findings are presented, clients indicate that this three-phase process fits their experience. Dependability was demonstrated with the data from the last three participants. Another researcher arriving at similar or comparable conclusions, given the data, perspective, and situation, can constitute evidence of dependability (Sandelowski, 1986). The results of an analysis, conducted by a

Master of Nursing student, of the data from the last three participants was comparable with those of the researcher. Other studies cited above provide additional evidence of the *tuning in* process and the development of client expertise through experiential learning.

Future research should include the participation of clients with non-insulin dependent diabetes or other chronic illnesses, to see whether they experience a similar integration process. If they do, then it is essential that changes be made in how clients with chronic illnesses are taught. For example, participants in this study saw themselves as diabetes experts. Those in the science of one phase had taken ownership of their diabetes and saw themselves on an equal footing with health professionals. They acknowledged that health professionals had a great deal of general knowledge about diabetes but were equally aware that they were experts in their own particular diabetes. They avoided encounters with nurses and other health professionals who might try to manipulate them or treat them in a pejorative manner. Traditional, adherence-based relationships will be unproductive in meeting desired health outcomes in those who have reached this level of integration.

The results of this study support the need for a change in client/educator relationships toward collaborative alliance relationships. This new role will have ramifications for educational strategies and the type and use of educational materials. Educators need to learn from their diabetic clients, in order to inform their practice, and to seek guidance about what roles would most benefit individual clients (Hernandez, 1995b).

This study provides an alternative understanding of how diabetes is perceived and incorporated into the lives and lifestyles of those who have it, and it challenges educators to re-examine current practices and learn to work collaboratively with their clients.

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A School-Based Self-Management Program for Youth with Chronic Health Conditions and Their Parents

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Un programme d'autogestion destiné à 65 jeunes atteints de maladie chronique et à leurs parents a eu lieu en milieu scolaire. Par une évaluation d'un groupe de pairs, on est intervenu sur les plans cognitif et comportemental afin de promouvoir l'autogestion par l'enfant des différentes tensions liées à la maladie chronique. On a aussi créé des groupes pour soutenir les parents lorsqu'ils aident leur enfant à utiliser les stratégies d'autogestion récemment acquises. Un devis pré et post test avec groupe de contrôle a examiné les effets du traitement sur la fidélité au traitement, la responsabilité personnelle de l'enfant et son efficacité personnelle. Les enfants au sein du groupe d'intervention, comparativement à ceux qui étaient dans le groupe de contrôle, montraient une fidélité au traitement bien plus élevée et davantage de responsabilité personnelle dans la gestion de leur maladie. Deux mois après, les enfants faisaient état d'un ralentissement de l'amélioration de leur responsabilité personnelle tandis que leurs parents estimaient que celle-ci restait importante. On n'a pas examiné de différence importante dans la mesure de l'efficacité personnelle. Il ressort également que les objectifs ont été atteints, que les enfants et les parents ont appris quelque chose et que les gens qui ont bénéficié de ce programme étaient satisfaits.

The Self-Management Program was a school-based intervention for 65 school-aged children with a chronic health condition and their parents. Through the peer group process, a cognitive-behavioural intervention was used to promote the child's self-management of the stresses associated with the chronic condition. Groups were also held to support parents in helping the child to use the newly acquired self-management strategies. A pre-and post-test waiting control group design examined treatment effects on therapeutic adherence, child self-responsibility, and child self-efficacy. Children in the intervention group, in comparison to those in the control group, showed significantly higher therapeutic adherence and more self-responsibility in the management of the health condition. By two months, the improvements in self-responsibility had begun to fade as reported by the children, but remained significant as reported by the parents. No significant differences were found on the self-efficacy measure. Goal attainment, child and parent learning, and consumer satisfaction were also found to be evident.

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Introduction

Schools are important centres for providing psychosocial and physical health services to children with chronic health conditions (Meeker, DeAngelis, Berman, Freeman, & Oda, 1986; U.S. Department of Health & Human Services, 1993). Thirty percent of children under 18 years of age are estimated to have chronic conditions (Newacheck, Stoddard, & McManus, 1993). Children with chronic health conditions typically have interrelated physical, psychosocial, and learning problems. Providing psychosocial services within the school setting might improve their accessibility, as only about 20% of children receive services for significant psychosocial problems (Mash & Barkley, 1989).

School-based health programs are best designed to address the commonly experienced needs of children, regardless of the type of chronic condition, as school children are likely to have various types of conditions. Such a non-categorical approach, focusing on the functional needs of children and their families, has been found to be a more meaningful way of designing psychosocial services than an approach based on disease-specific diagnoses (Stein, Bauman, Westbrook, Coupey, & Ireys, 1993).

For youth to cooperate with their parents in caring for their health needs, two major competencies have been found to play a significant role: management of the stresses associated with the chronic condition, and performance of the health-care tasks associated with the condition (McNabb, Wilson-Pessano, & Jacobs, 1986). If interventions are designed to improve only the youth and family's knowledge and skills relevant to the condition, adherence to the health-care regimen typically remains problematic (Heerman & Wils, 1992; Karoly, 1993). Adherence rates for youth on long-term therapeutic regimens average about 50% (LaGreca, 1989). Adherence difficulties do not uniformly lead to impaired health; however, they are related to extended illness, further cost, and physical complications (Krasnegor, Epstein, Johnson, & Yaffe, 1993; Masek & Jankel, 1982). Development of self-management competencies can serve to facilitate progression of the child's physical health and psychosocial functioning (Masek & Jankel; Stein & Jessop, 1989).

Self-management interventions have been found to produce behavioural change in children (Delameter, 1993). The majority of intervention studies have targeted health-care tasks associated with a specific condition, particularly diabetes and asthma. They have varied in the type, intensity, and duration of intervention strategies, as well as the outcomes targeted, the age of the youth, and the severity of the disease.

Although these studies have methodological and design limitations, results indicate that the health perceptions and health behaviours of the children can be improved (Agras, 1993; Lewis, Rachelefsky, Lewis, de la Sota, & Kaplan, 1984). The design of most intervention studies directed toward children include only one or two self-management skills, rather than the complete skill package.

Self-management is the ability of the individual to use self-regulatory skills to manage developmental, health, and situational challenges (Károly & Kanfer, 1982). Self-regulatory skills comprise self-observation, self-instruction, self-monitoring, decision-making, self-evaluation, and reinforcement (Bandura, 1986). Intervention programs that incorporate self-management approaches and target children's health perceptions and behaviours offer promise for health outcomes (Petosa, 1986; Taggart et al., 1991).

Purpose

The purpose of this study was to evaluate the effectiveness of a self-management, school-based intervention for youth. The following research questions were posed:

- In comparison to the children in the control group, will the children in the experimental intervention group exhibit greater improvement in health perception and health behaviour?
- Will the intervention children and parents achieve their individualized health goals?
- Will the intervention program result in consumer satisfaction and learning?

Theoretical Basis for the Intervention

The intervention was based on a social-cognitive paradigm (Bandura, 1986) and a stress and coping paradigm (Lazarus & Folkman, 1984). The social-cognitive paradigm influenced conceptualization and implementation of the self-management strategies. Self-management was defined as the use of self-regulatory skills for enhancing stress management and building parallel construction of self-efficacy. Self-regulatory skills were designed to enhance *self-observation* of psychophysiological reaction to stress; *self-monitoring* of the events that produce the stress response; *self-instruction*, to guide oneself in stress management behaviours that reduce, inhibit, or change the stress response; *decision-making*, to determine which skill is likely to be the most appropriate for the sit-

uation; *self-evaluation*, to identify the usefulness of the skill used; and *self-reinforcement* of the effort and outcome reached. Changes in the youth's abilities to self-regulate are linked in theory to self-efficacy, which is defined as the perception that one has the ability to manage daily challenges (Bandura).

The stress and coping paradigm provided the framework for the intervention content. The youth's adherence and physiological responses are influenced by stress (Boardway, Delmeter, Timakowsky, & Gutai, 1993; Johnson, 1990). Stress associated with the chronic condition may occur due to treatments, interactions with peers, conflicts with parents, or fear of relapse. Children's avoidant styles of coping, such as detachment and wishful thinking, have been found to be linked to ineffective management of the chronic condition (Auerbach, 1989). Strategies for the self-management of emotions and alteration of the stressful situation were taught to the children in the intervention.

The intervention incorporated emphases on (1) the full range of self-regulatory skills, (2) the child's health perception and health behaviours, and (3) mind-body linkages. These approaches are consistent with the recommendations for child-oriented cognitive interventions (Beck, 1993; Kazdin, 1993; Mahoney, 1993).

Method

Participants

Two school districts agreed to participate in the study. School personnel, including nurses, teachers, psychologists, and counsellors, identified children with chronic health conditions. Ninety-two percent of the parents and children who were notified agreed to participate. The remaining 8% declined because of schedule conflicts or the possibility that they would be moving out of the school district in the near future. The 65 children and their parents who agreed to participate met the screening criteria; thus the children involved had no serious mental health or cognitive disorder. Their types of chronic condition were primarily long-term physical illnesses such as asthma, arthritis, cystic fibrosis, diabetes, allergies, recurrent headaches, or chronic abdominal pain. Common reasons for referral to the study intervention were child-adherence and self-management problems or stress responses to the chronic health condition. Every child's health condition was evaluated by his or her physician, who approved participation in the study.

The mean age of the children was 9.5 years (range 7-13 years). The median grade was Grade 4 (range of Grade 2 to Grade 8). The mean age

of the fathers was 40 years and the mean age of the mothers was 37 years. Fourteen children (21%) came from families whose parents were divorced, separated, or widowed. The majority (92%) of the children were Caucasian. Family income ranged from \$5,000 to more than \$50,000 per year, with a mean range of \$25,000 to \$29,000. The average education level for mothers and fathers was technical training beyond high school. The children in this study had no other support services immediately prior to or during treatment.

Design

Approval was obtained from the University of Washington Human Subjects Review Committee, according to whose guidelines the completed parent consents and youth assents noted that all participants would receive the intervention at some time during the study. Thus a quasi-experimental pre- and post-test, waiting control-group design was used. Families were randomly assigned to either the intervention or the waiting control group, except for a few families (11%) who requested to be in the waiting control group because of their schedules. Those families who requested a delay in the intervention were not found to differ significantly from the total sample. No family dropped out of the study. The intervention group comprised 29 children, the waiting control group 36 children. Four intervention groups were treated in the fall, with the waiting control groups treated during the winter.

The subjects were divided into treatment groups of six to eight members, to ensure adequate group process. Children were assigned to a treatment group in accordance with their age and geographic location. Since children represented 17 different schools, the intervention was held in centralized school settings.

Measures of moderating variables that could influence the dependent variable were obtained prior to the intervention. The dependent variables were measured immediately before, immediately after, and two months after the intervention. Data were collected in each family's home by graduate students in pediatric nursing who had clinical experience with children with chronic health conditions and their families. Data collectors attended a 40-hour training session and participated in biweekly two-hour supervisory meetings. Families were asked not to inform the data collectors of the time period in which they received the intervention, and the data collectors had no contact with the nurses who carried out the intervention.

The study's research design has particular merit for eight reasons: (1) treatment integrity was monitored throughout the study; (2) the nurses who provided the intervention were not those who collected the evaluation data; (3) child and parent learning from and satisfaction with the program were measured; (4) the child and the parent were independent sources of information for the health outcomes, with agreement of results examined; (5) health outcomes were measured in relation to the child's particular condition, to assess the program relative to the child's daily life; (6) the health behaviour of self-responsibility was differentiated into two components – the cognitive process of decision-making and the implementation process of administering the health-care task; (7) health perception and health behaviour were study outcomes; and (8) moderator variables were measured and statistically controlled for their potential influence on the intervention.

Intervention Conditions

Intervention administration, content, and format. The self-management intervention program had three components: (1) a single two-hour family session held in the home prior to treatment; (2) a dozen 75-minute youth-group sessions, held twice a week for six weeks; and (3) three 90-minute parent-group sessions, held biweekly over six weeks. During the *home session* the group leader helped the child and parent negotiate and develop a contract, using a modified approach to Kiresuk's (1976) goal-attainment scale. The contract included a concern, a desired goal with a measurable behavioural change, action steps, and positive reinforcement approaches. The contract was relevant for the youth's health condition and the intervention. It was used during the group intervention as a way to tailor the curriculum to each child's experience of the chronic condition. The group facilitator telephoned the parents during the intervention to reinforce their participation in the contract and address the matter of any required changes.

Child-group sessions were held in the school, to enhance accessibility and normalization of the intervention. Each session had three parts: (1) warm-up and review (15 minutes); (2) knowledge and skill development (45 minutes), with demonstration, practice, and feedback strategies; and (3) application to the home and school setting through homework assignments, role playing, and completion of handouts (15 minutes). Training in self-regulatory skills and reinforcement by peers and group leaders were incorporated into each session. Periodic sessions were devoted to synthesis and integration of learning. The child-intervention content included the following topics: "I can take

care of me" concept; mind-body connection; individual differences in stress responses; thoughts and feelings regarding "stress triggers"; constructive expressions of stress; relaxation to manage stress; problem-solving; communication to elicit help; positive self-talk; and self-management to "take care of me."

Parent-group sessions were held at a centralized school location. These sessions focused on enhancing parental understanding of child intervention and encouraging parental coaching and reinforcement of the child's use of the newly acquired self-regulatory skills. The group leader used an educational format to describe the intervention that the children were receiving. The parents, facilitated by the group leader, generated problem-solving and approaches promoting the child's use of new skills.

Two graduate nursing students led the child groups. A nurse with a doctoral degree facilitated the parent groups. Each nurse had clinical experience working with children with chronic health conditions and their families. Prior to the intervention, the group leaders completed a one-week training session on group process skills and the intervention content.

Intervention integrity. The content and process of the intervention were monitored and sustained by seven approaches, to assure treatment integrity: (1) A *curriculum manual*, entitled *You Can Take Care of Yourself*, was developed, including objectives, content, learning activities, and teaching strategies for each session (Cowan, Brandt, & Magyary, 1988). (2) A *content checklist* for the curriculum was completed by the group leaders at the end of each session. (3) *Weekly supervisory meetings* were held with the group leaders and the principal investigators. The in-session notes completed by group leaders were used during these meetings as a means of preparing for the next sessions. (4) Each child's *participation as an individual* in the group was evaluated after each session by the group leaders on five process dimensions: interest; receptiveness; understanding; involvement in practice exercises in the classroom, home, and school; and completion of homework. (5) Each child and parent session was evaluated on *group process dimensions* of cohesion, cooperation, communication, productivity, emotional involvement, cognitive involvement, and conflict. (6) After each child and parent session the group leader completed a self-evaluation on *leadership roles* as instructor, facilitator, supporter, coordinator, communicator, and energizer. (7) The child-group sessions were randomly selected for *videotaping* early, mid-point, and late in the intervention program. The purpose of videotaping was to facilitate improvements for future

sessions and to provide for a cross-validity check of the group process evaluations by the group leaders. The group evaluation forms for this study were developed using the principles of group process described by Johnson and Johnson (1987).

Sixty-two percent of the children attended the maximum of 12 sessions; 38% missed one or two sessions. On average, 90% of the curricular content was delivered as planned. Mean ratings of individual child participation in the group process ranged from moderately high to very high on interest, receptiveness, and understanding. Completion of homework and practice of strategies at home or in school were consistently rated low to moderate. Mean ratings of the child-group process dimensions ranged from moderately high to high. Mean ratings of parent-group sessions ranged from moderate to high. The group leaders' ratings of group process were consistent with the evaluation of the videotapes conducted by an independent rater. Self-performance ratings by the respective group leaders were moderate to high. No significant differences on performance were found across the group leaders or across the groups of children or parents.

Measures

Measures were obtained on the following: family and child characteristics, child health behaviour, child health perception, health-goal attainment, child and parental learning, and child and parental satisfaction with the intervention.

Family and child characteristics. Potential moderators of the intervention effects were selected on the basis of theoretical and empirical work. The child's mother completed the measures of child and family characteristics. Family characteristics selected were family income, education, and stresses. *Income and educational* variables were viewed as resources that influence the child's experience of stress and interest in learning (Lazarus & Folkman, 1984). Family stresses influence the nature of the child's environment and interactions with others, and thus may affect the potential for the child's behavioural and attitudinal change (Campbell, 1990; Rutter, 1994). Two types of *family stress* were identified via questionnaires with established validity and reliability. The family's major life changes were measured using the Family Inventory of Life Events (FILE), by McCubbin, Patterson, and Wilson (1981). Situational stresses related to the child's chronic condition were measured using the Impact of the Illness on the Family (Stein & Riessman, 1980).

Child characteristics identified as potential moderators were age, gender, and severity of illness. *Gender* differences with respect to chronic health conditions have been reported in the literature. For example, female teens with a disability, and their parents, have been found to experience more difficulty performing daily activities than their male counterparts (Walker & Greene, 1991). *Age* affects adherence differently, according to the chronic condition. Adherence has been found to decrease with age in children with diabetes (Anderson, Auslander, Jung, Miller, & Santiago, 1990) and to increase with age in children with cancer (Manne, Jacobson, Garfinkle, Gerstein, & Redd, 1993). *Severity of illness* may alter the child's self-efficacy in association with the lack of predictability in ongoing experiences and the development of learned helplessness (Kuttner, Delameter, & Santiago, 1990). The Healy Scale was adapted for this study to measure the degree to which the child's chronic health condition interfered with daily functioning (Healy, McAreavey, & Von Hippel, 1978).

Health behaviour outcomes. Therapeutic adherence and self-responsibility were measured using a structured clinical interview entitled "Health Adherence and Management Interview" (Magyary, 1988a). The child was interviewed independently of the parents.

The Health Adherence and Management Interview was advantageous in two ways. First, the format allowed for the interview to be conducted in relation to a variety of health conditions, in contrast to instruments that focus on a specific disease. Second, self-responsibility was delineated into two components: decision-making and administration. Measuring responsibility for decision-making separate from administration delineates the child's developmental progression of self-responsibility and clarifies how individual families manage the condition (Wysocki, Meinhold, Cox, & Clarke, 1990). For example, a child with a chronic health condition may not share responsibility with a parent for decisions about a medication dosage, but rather be totally responsible for administering it.

A percentage score was generated by the Health Adherence and Management Interview for three variables: therapeutic adherence, self-responsibility for decision-making, and self-responsibility for administration. The percentage for the *adherence* score was obtained by having the respondent specify which of the following health-care components were relevant to the child's condition: medication, special treatment procedures, monitoring procedures, exercise, modification of daily activity, diet, coping strategies, and scheduled visits/phone calls to health professionals identified by the respondent. The number of times

per week the health-care component was prescribed, as well as the number of times per week the health-care component was actually implemented, were identified by the respondent. The frequency of implementation was divided by the frequency of prescription to generate a percentage adherence score for each of the prescribed components. The percentage scores were then averaged across the health-care components.

The *self-responsibility score on decision-making* was obtained by asking the respondent to rate on a grid the extent to which the child actively participated in decision-making in each identified health-care component. The 10-point grid scale, with 10 as high, was converted into a percentage score for each identified component. A mean percentage for self-responsibility in decision-making was generated by averaging the scores for the identified health-care components. At the follow-up points, the respondent was asked to note any changes on the previously rated grid.

The *self-responsibility score on administration* was obtained by asking the respondent to repeat the above procedure, but now marking the extent to which the child participated in the administration of each identified component. A mean percentage score was then calculated for self-responsibility for administration.

Health perception outcome. *Self-efficacy* was defined as the child's perception that daily life stresses could be handled by his or her learning and using self-management strategies. The Youth Self-Efficacy Scale (YSES), by Magyary (1988b), consists of 31 items with a yes/no format. A percentage score was generated, with high scores indicating high self-efficacy. The internal consistency coefficients (Cronbach's alpha) on the YSES across three time points ranged from .83 to .91. Construct validity was demonstrated by correlations of $r(65) = .30, p < .01$ between the YSES and the Child Health Locus of Control Instrument (O'Brien, Bush, & Parcel, 1989), and $r(65) = .24, p < .05$ between the YSES and the self-worth subscale on the Perceived Self-Competence Instrument, by Harter (1985). These validity results suggest that self-efficacy as measured by the YSES is related to other measures of the self-system but appears to have conceptual distinctness from self-worth and health locus of control.

Health goal attainment. An adaptation of the Goal Attainment Form, by Kiresuk (1976), was completed by the parents at the last assessment time. During the home session, the health goal was negotiated by the parent and the child and the desired level of attainment was

determined using a five-point scale, 1 indicating "much less than expected" and 5 indicating "much more than expected."

Child and parent learning. Measures of child and parent learning of the intervention curriculum were developed for this study. *Child learning* was measured in three ways. First, each child evaluated his or her own learning at the end of the intervention by means of a 17-item questionnaire; the extent to which the child applied program knowledge and skills to daily living and learned to "take good care of myself" was measured. Second, parents evaluated the child's learning by rating on a five-point scale (5 as high) the extent to which the child demonstrated knowledge and skills before and after treatment. Third, the group leaders evaluated the child's knowledge and mastery of skills by means of a 49-item checklist, with a rating scale of 1 (minimal evidence) to 5 (considerable evidence). *Parental learning* was measured at the last parent session by means of a 10-item questionnaire.

Consumer satisfaction. Measures of *Child's Satisfaction* and *Parent's Satisfaction* with the intervention program were obtained at the last assessment by using Likert-scaled items and several open-ended questions. Parents completed the ratings separately from the children.

Results

Preliminary Analyses

Data collectors. At each assessment, the data collectors noted whether they knew if subjects were assigned to the intervention or to the waiting control group. The percentage of data collectors who indicated they did not know subject assignment was as follows: 91% pre-treatment, 77% immediately post-treatment, and 42% at two months post-treatment. Those data collectors who knew the subject placement stated that a family member had provided the information. ANOVA analyses indicated that the pre-treatment and post-treatment outcome measures did not differ across the five data collectors.

Covariates: child and family characteristics: T-tests were used to determine whether the intervention and waiting control groups differed on interval variables. Chi square tests were used for the categorical level moderator variables. Significant differences were found for child's gender ($\chi^2 (1, N = 65) = 4.01, p < .04$) and major family life changes ($t (65) = 2.20, p < .03$). Families in the intervention group had more female than male children and had experienced more major family changes. While child gender was significantly related to nearly half of the outcomes, major family changes were rarely related to any

of the outcomes, and child gender and family stress were significantly, but minimally, interrelated ($r(65) = .21, p < .05$). Thus child gender was selected as a covariate to test for intervention efficacy. No significant differences were found between the intervention group and the control group on maternal or paternal educational level, total family income, the impact of the child's health condition on the family, the child's severity of health condition, or age. Hence these variables were not used as covariates.

Covariates: pre-test scores for dependent variables. No significant differences were found when t -tests were used to determine whether the intervention group differed from the waiting control group on pre-test scores for dependent variables. However, pre-test scores on outcomes were used as covariates because of their high correlation with the two post-tests across time. The correlation coefficients ranged from $r(65) = .51$ to $.89$, with $p < \text{value}$ ranging between $.01$ and $.001$.

Intervention Effects

Health behaviours and health perception. One factor analysis of covariance was used to evaluate treatment effects using the pre-test score and the child gender as covariates. A one-tailed significance test was used (see Table 1). Because of the exploratory nature of the study, each post-treatment time point was evaluated separately to avoid confounding one time point by the other. Missing data for any single analysis ranged from 0% to 6% of the sample. Only patterns of findings were determined noteworthy for discussion, as significant findings due to chance may occur because of the number of analyses.

Children in the intervention group, in comparison to those in the waiting control group, exhibited significantly higher scores on therapeutic adherence. This finding was corroborated by both child and parent report at the immediately post-treatment and two months post-treatment points. Children in the intervention group also exhibited more self-responsibility than controls in management of the chronic condition, as measured on both self-responsibility outcomes – decision-making and administration of the health-care regimen. This pattern of results was evident based on the child report immediately post-treatment and the parental report at both time points. No significant differences were found on the child self-efficacy measure. These results were stable when analyses were compared with and without outliers – scores greater than three standard deviations from the mean. Clinical significance of the results is discussed in the next section.

Table 1 *One-Factor Analysis of Covariance:
Child health outcome percentage score*

	Adjusted <i>M</i>		<i>F</i>	<i>p</i> <
	Treatment	Control		
Immediately Post-Treatment				
Therapeutic Adherence				
Parent Report	73	62	4.78	.02
Child Report	90	66	12.78	.00
Child Self-Responsibility				
Decision-Making				
Parent Report	72	64	4.90	.02
Child Report	74	70	2.33	.06
Administration				
Parent Report	80	67	10.08	.00
Child Report	77	70	4.84	.02
Child Self-Efficacy	81	85	1.10	.15
Two Months Post-Treatment				
Therapeutic Adherence				
Parent Report	74	51	5.50	.01
Child Report	87	65	7.35	.00
Child Self-Responsibility				
Decision-Making				
Parent Report	73	62	9.11	.00
Child Report	69	70	.05	.41
Administration				
Parent Report	77	67	9.60	.00
Child Report	74	70	1.62	.10
Child Self-Efficacy	83	81	.41	.26

Health goal attainment. On the health-goal attainment scale, every parent noted at least one change in child health perception or health behaviour as a result of the intervention. The majority of parents reported two or more improvements. Scores ranged from "expected change" to "much more than expected change." Typical examples of health goals negotiated between child and parent are as follows: improvement in health-related symptoms; increase in age-appropriate responsibility for health-care tasks; and increase in positive behavioural responses to the health condition. Parents reported a significant decrease in the frequency and severity of the child's health problems after treatment ($t(29) = 10.72, p < .00$).

Child and parent learning. Child learning results were consistent across independently derived sources of evaluations: child, parent, and group leaders. Nearly all of the children reported a moderate to high level of acquired self-management knowledge and skills. Children reported attempts to transfer and use the newly acquired skills in the home and school setting, but consistent mastery of skills was rarely reported. The majority of parents reported a moderate to high level of child learning after the intervention. Parent ratings showed a significant increase from pre-treatment to post-treatment on child health knowledge and health-appropriate behaviours ($t(29) = 6.52, p < .001$). Mean score ratings by the group leaders on child learning indicated "considerable evidence" that children understood new information and attempted to apply this knowledge to specific skills. Knowledge and skills scores correlated at $r(29) = .87, p < .001$. Although group leaders rated as high the children's use of new skills during the child group sessions, they rated as moderate the generalization of new skills to daily living. Child, parent, and group leader ratings on child learning were significantly correlated in a positive direction with the majority of scores on the outcome measures.

Results on *parent learning* were similar to the data patterns on child learning. Parents reported a high level of understanding of the intervention curriculum and a moderate level of ability to transfer this understanding to daily living. Parents requested additional assistance in fostering the transformation of the child's learning into sustained behavioural patterns.

Consumer satisfaction. All the children and all the parents rated the intervention as very informative, relevant, and useful. Many children and parents indicated that more initial and follow-up sessions were needed to facilitate generalization of newly acquired skills to daily living. The majority of children and parents believed that in future interventions the school personnel should be involved, to facilitate transfer of the child's newly acquired skills to the school environment.

Patterns among Outcomes

Intercorrelations between child-reported and parental-reported score on the corresponding outcomes were significant. The correlational coefficients ranged from $r(29) = .36$ to $.52$ at the $p < .05$ to $.001$, a two-tailed level of significance. Although the parental and child outcomes were related, they appeared to be somewhat independent, since a minimal degree of variance (13% to 27%) was shared.

The intercorrelations among the majority of parent-reported outcomes were significant. The Pearson correlations ranged from .38 to .58 ($p < .01$ to .001). In contrast, the majority of intercorrelational patterns among the child-reported outcomes were not consistently significant.

Discussion

A summary of the results and implications for further research are discussed in relation to the intervention utility, efficacy, strength, and conceptualization (Seligman, 1995; Yeaton & Sechrest, 1981). In relation to *utility* of the self-management intervention, children and parents perceived the intervention as useful to their lives. The high attendance rate also attests to the intervention's value. Children and parents frequently remarked that holding the intervention in the school setting increased its accessibility and conveyed the message that management of a chronic health condition is one of the many life skills taught in school.

Evidence of intervention *efficacy* was found for the attainment of health goals and improvement on the outcomes of therapeutic adherence and child self-responsibility. The child's learning during the intervention was found to be significantly and positively related to therapeutic adherence and self-responsibility. Despite these positive results, the *strength* of the intervention dosage needed to be enhanced for the child self-responsibility outcome. Treatment efficacy was sustained for therapeutic adherence but not self-responsibility, as reported by the child. The significant improvement in self-responsibility behaviours, as reported by the child, had begun to fade by the time of the two months post-intervention follow-up. Although the parents perceived sustained change at this point, they concurred with the children that increased initial and follow-up sessions would have helped to reinforce the child's use of self-management skills in the home. In addition, the intervention possibly would have been strengthened had the child group sessions and parent group sessions been augmented by more individualized family sessions. Parents and children found that the process of contracting for a mutually agreed upon health goal was both rewarding and challenging. They believed that more practice and professional guidance would help solidify the skills developed during contracting. Strengthening the skills of family members, in relation to the child's condition and in the context of family dynamics, may enhance the ongoing use of these new skills (Anderson & Coyne, 1993).

Involvement of school personnel was viewed as a means of strengthening the intervention. If school personnel were to participate in the intervention, the efforts of children could be reinforced, and they could

receive feedback on their attempts to use new skills in the school environment. Other child interventions have found that generalization and maintenance effects are more readily obtained when the consequences of positive behaviours and monitoring occur naturally in the school as well as in the home (DuPaul & Eckhart, 1994). Further investigation is needed to enhance our understanding of which intervention strategies will sustain and reinforce the generalization of new behaviour patterns (McGinnis, 1993).

The intervention program raised issues regarding the *reconceptualization of responsibility for health management*. During the intervention, it became strikingly apparent that child self-responsibility is best understood in the context of *joint* responsibility by parent and child. A critical element for the successful attainment of the contracted health goal was found to be the ability of parent and child to negotiate the distribution of responsibilities. For many parent and child dyads, joint management, with a gradual increase in the youth's responsibilities for the health condition, was the contracted goal. The group leaders discovered that few parents viewed the child's participation in health management with clear parameters or developmental considerations. Some parents expected to transfer responsibilities to a child who was not prepared to accept them or who did not show readiness indicators. Others were reluctant to relinquish responsibilities to the child. The progression of responsibilities for health management needs to be more fully understood with respect to group norms as well as individual differences among children and parents (Giodarno, Petrila, Banion, & Neuenkirchen, 1992). Discovering strategies that promote effective sharing of responsibilities among youth and parents will be valuable, given that the health status of children is influenced by supportive family environments (Follansbee, 1989).

Measurement of responsibility for joint management poses a challenge for intervention studies. In our study, the parent's and the child's perceptions of responsibility were not always consistent. Other researchers have also found parent and child reports on child behaviour to differ (Achenbach & Edelbrock, 1983). There may be a variety of explanations for these differences. In our data set, perhaps parents identified small changes in the child's behaviour, whereas the children overlooked changes. In this instance, child-reported data may be less reliable, given that the various dimensions of self-management were not consistently interrelated as an overall construct. Another hypothesis is that the child's perception of change is more accurate than the parent's. In this study, children frequently reported frustration with using newly acquired self-management responsibilities in the school. School situa-

tions are not observed by parents. Thus children may perceive differently, since they are summarizing their behaviours across situations. Research needs to be directed toward the reasons for differences between parent and child perceptions of child behaviours.

Another issue raised by this study is the *conceptualization of self-efficacy*. The lack of change in self-efficacy may be best understood from a developmental and interactional perspective. The child's environment interacts with the child's mastery and interpretation of experiences to develop and sustain belief patterns incorporated into the self-system (Harter, 1988). Thus treatments intended to alter a child's self-schema require great strength and long duration (Kazdin, 1993). Too often, the effort, time, and intensity required to alter one's self-schema are underestimated (Fonagy & Target, 1996; Seligman, 1994). Perhaps self-efficacy needs to be conceptualized as a secondary outcome contingent on the sustained improvement of primary outcomes such as health behavioural patterns of adherence and management. A causal modelling perspective may contribute to our understanding of the interrelationships of primary and secondary outcomes.

In summary, the design of intervention studies aimed at improving child health perceptions and behaviours needs to consider the complexities involved, as well as the strength of the intervention required for change to occur and be sustained over time. In today's health-care climate of cost-containment and economy of time, there may be a tendency to underestimate the comprehensiveness needed. A course of treatments designed to improve adherence and self-responsibility over time may be more cost-effective than one treatment so brief that the benefits dissipate quickly.

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The Influence of Early Biological Risk and the Home Environment on Nine-Year Outcome of Very Low Birth Weight

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On a examiné les effets d'un risque médical tôt dans la vie et d'un milieu de vie à la naissance et à l'heure actuelle sur les résultats cognitifs et scolaires de 35 enfants âgés de neuf ans dont le poids à la naissance était extrêmement faible, et que l'on a suivis dans cette perspective. On n'a pas trouvé de relation évidente entre les mesures du risque médical tôt dans la vie et celles des résultats. La qualité du milieu de vie expliquait la moitié des variances au niveau des résultats. Cinq sujets ont montré à la longue une association constante avec les résultats positifs, ce sont la sensibilité des parents aux besoins des enfants (*parental responsivity*), le soutien des parents pour l'apprentissage, l'engagement des parents envers leur enfant, le fait d'être exposé à diverses situations et la présence d'une figure paternelle.

The contributions of early medical risk and the early and contemporary home environment on cognitive and academic outcomes of 35 nine-year-old survivors of very low birth weight (VLBW) who were followed prospectively were investigated. There were no significant relationships between the measures of early medical risk and outcome. The quality of the home environment accounted for half of the variance in outcome. Five themes that showed consistent associations over time with positive outcomes were: parental responsivity, parent support for learning, parent involvement with the child, exposure to a variety of experiences, and the presence of a father figure.

Children born prematurely with a very low birth weight (VLBW $\leq 1,500$ grams) are assigned a high-risk developmental status because of their intrinsic vulnerability during infancy. This vulnerability has its origins in their immature physiological and biobehavioural systems and their exposure to medical complications. These children may be at continued risk during their school-age years because of subtle deficits in their information-processing abilities (Klein, 1988; Klein, Hack, Gallagher, &

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Fanaroff, 1985; Schraeder, Heverly, O'Brien, & McEvoy-Shields, 1992). Also, immature behaviour (Breslau, Klein, & Allen, 1988; Ross, Lipper, & Auld, 1990; Schraeder, Heverly, & Rappaport, 1990) may compromise their ability to perform well in the classroom.

It has been proposed that while all children require a supportive environment to develop optimally, high-risk children are especially sensitive to environment (Aylward, 1992). Nonsupportive environmental effects on vulnerable children have been referred to as "the continuum of caretaking casualty" (Sameroff & Chandler, 1975). A nonsupportive environment can amplify the risk status of vulnerable children. Conversely, from this perspective, vulnerable children reared in optimum environments can thrive and overcome their original and ongoing disadvantages.

While conceptually the environment is believed to influence outcomes of high-risk children, empirical work in the area has concentrated on describing the effects of structural measures of the environment – for example, social-risk indices such as socioeconomic status (SES), ethnic-minority status, mother with less than high school education, and single-parent family – on child development (Hack et al., 1992; Ross, Schechner, Frayer, & Auld, 1982; Vohr, Garcia-Coll, & Oh, 1989). The preponderance of studies examining social risk or SES on low-birth-weight developmental outcomes report that these social/structural variables explain little about developmental status during the first year of life. Structural variables become more strongly associated with developmental outcomes as the child matures and measures of development become based on language and problem-solving (Aylward, 1992). Structural variables may have value in screening programs for quickly identifying populations at risk, but by their nature they are epiphenomenal and as such do not have explanatory value. They are probably proxy measures of processes in the environment that influence development.

Despite the strong evidence that environmental factors are more important than biological risk factors in predicting or explaining developmental outcome after the first year of life of VLBW children, relatively few studies have described environmental processes essential to optimal outcome (Schraeder et al., 1990; Siegel, 1982). Knowledge about specific environmental processes, the time frame in which they are most critical, and the developmental processes they are most likely to affect is important to practitioners and to policy-makers, who have a stake in promoting children's optimal development (Aylward, 1992).

The purposes of this study were to describe the contributions of early and contemporary environmental-process variables and perinatal medical-risk status to development during the first nine years of life of VLBW children. Specific questions posed concern the influence on outcome of early biological risk; the contribution to outcome of the early and contemporary environment; and the specific early and contemporary environmental processes that influence outcome. The children were studied prospectively using a model predicated on the notion that development in children at early biological risk transcends any single variable such as birth weight or medical illness during the perinatal period and evolves from the dynamic relationship between the child and specific aspects of the environment (Aylward & Kenny, 1979).

Method

Study Design and Procedure

This report uses a descriptive correlational design to examine the effects of the environment and early medical risk on a cohort of children studied longitudinally. Environmental and developmental data described in this report were gathered during home visits when the children were six, 12, 24, and 36 months corrected gestational age, and four, five, and nine years chronological age. During each visit, rapport was established with the mother and informed consent was obtained. The project nurse obtained information concerning the environmental-process variables and a licensed psychologist administered the K-ABC, the VMI, and the PIAT-R. The K-ABC and the VMI were administered within one month of the child's ninth birthday and the PIAT-R was administered following the child's completion of the academic year, because the PIAT-R is sensitive to the cumulative effects of learning.

Data on the biological-risk variables (number of days on mechanical ventilation; length of stay in the intensive-care nursery; birth weight) were obtained, at the beginning of the study, from the original medical record. Intraventricular hemorrhage (IVH) status was determined by a board-certified neuroradiologist who rated the children's ultrasounds or brain scans for the presence of IVH using a well-recognized and validated clinical 0-to-4 rating scale (Papile, Burstein, Burstein, & Koffler, 1978). Of the 35 children, 20 had no evidence of IVH, four had grade 1, and seven had grade 2 hemorrhages. Four children did not undergo scanning. The mean number of days the children received mechanical ventilation was 6.43 (range 0 - 39; $SD = 9.64$). The mean length of stay was 51 days (range 11 - 93; $SD = 21.68$) and the mean birth weight was 1,214 grams (range 780 - 1,500; $SD = 192$).

Subjects

The subjects were 35 children and their primary caregivers who were recruited at the child's birth. The sample was obtained from census books at four nurseries for babies born between August 1982 and May 1983 at birth weights of 1,500 grams or less (Schraeder, 1986; Schraeder et al., 1990). Infants recruited into the study were appropriate for gestational age as assessed by the Dubowitz scale (Dubowitz, Dubowitz, & Goldberg, 1970), free from congenital anomalies, and discharged home from the nursery before six months of age. Of 64 potential subjects, two refused to participate, five children were inappropriate for gestational age or had a major congenital anomaly, and 16 could not be located, leaving 41 infants. The mean birth weight of the sample was 1,204 grams ($SD = 197$; range 780 - 1,500). One family was lost to the study in the second year. In a second family, the mother refused participation except for telephone interviews during the sixth year of the study. Four subjects were excluded from this analysis because they had severe developmental delay with neurological deficits and could not be assessed using the cognitive and academic measures selected for this study. See Table 1 for the characteristics of these children.

Data from the remaining 35 children were used in this analysis. Twenty children were girls and 15 were boys. Twenty were Caucasian and 15 were African American. Forty-one percent of the children were reared in households headed by single, unemployed mothers or by parents who were marginally employed in unskilled jobs.

Table 1 *VLBW Children Excluded from the Analysis Because of Severe Developmental Delay (N = 4)*

Subject	Gender	Race	Medical Diagnosis	Test results
#1	Male	White	Spastic quadriplegia; hydrocephally	Vineland < 20 (Profound deficit)
#2	Male	Black	Spastic quadriplegia; epilepsy	Vineland < 20 (Profound deficit)
#3	Male	Black	Blind with hydrocephally	Vineland < 20 (Profound deficit)
#4	Female	White	Microcephally with undifferentiated neurological dysfunction	Vineland = 53 (Moderate deficit)
Vineland = Vineland Social Adaptive Scale (Sparrow, Balla, & Cicchetti, 1984)				

Instruments

Process Measures of the Environment

Home Observation for Measurement of the Environment (HOME – birth to three years) (Caldwell & Bradley, 1984) was used to assess aspects of the home environment at six to 24 months corrected gestational age. The 45-item scale assesses six areas: (a) emotional and verbal responsiveness, (b) avoidance of restriction and punishment, (c) organization of the physical and temporal environment, (d) provision of appropriate play materials, (e) maternal involvement with the child, and (f) opportunities for variety in daily stimulation.

The scale provides subscales and a total score. The scale was standardized on a study of 174 families that were heterogeneous in racial composition, educational achievement, and economic status. Internal consistency ranged from a low of .44 to an adequate .89 for the subscales and was .89 overall. Test-retest reliability from six to 12 months ranged from .29 to .62 for the subscales and was .62 overall. Construct validity was established by correlations with socioeconomic variables such as educational level and crowding in the home as well as correlations with mental-test scores (Caldwell & Bradley, 1984).

Interrater reliability for this study was established using procedures described in the HOME manual, and was .95. The mean HOME scores at six, 12, and 24 months were 32.8, 34.5, and 36.8, respectively. The means place the subjects in the 50th percentile when compared with the standardization population, with a range from the 10th to the 75th percentile.

Home Observation for Measurement of the Environment (HOME – preschool) (Caldwell & Bradley, 1984), an upward extension of the HOME – birth to three years, was used to assess the quality of the home when the children were three to five years. The 55-item scale assesses eight areas: (a) stimulation through toys, games, and reading materials; (b) language stimulation; (c) physical environment; (d) pride, affection, and warmth; (e) stimulation of academic behaviour; (f) modelling of social maturity; (g) variety of stimulation; and (h) physical punishment. Validity and reliability are well established (Caldwell & Bradley; Elardo & Bradley, 1981). For this sample, interrater reliability was .94 and internal consistency was .92. The mean HOME – Total score at 36 months was 41.1; at 48 months, 39.7; and at 60 months, 41.8.

Home Observation of Families of Elementary School Children (HOME – E), the upward extension of the infant and preschool HOME, was used to measure the quality of the home environment at nine years

of age. The eight subscales measure (a) emotional and verbal responsiveness, (b) encouragement of maturity, (c) emotional climate, (d) growth-fostering materials and experiences, (e) provision of active stimulation, (f) family participation in developmentally stimulating experiences, (g) paternal involvement, and (h) aspects of the physical environment. Validity and reliability are well established (Caldwell & Bradley, 1984).

Interrater reliability for this sample was .96 and the coefficient alphas ranged from a low of .40 for family participation in developmentally enhancing experiences to .77 for paternal involvement. Internal consistency for the entire scale was .89. The mean HOME - Total at nine years of age was 40.8.

Developmental Outcome Measures

Kaufman Assessment Battery for Children (K-ABC) measures cognition as expressed in mental-processing abilities and achievement. The test yields five major scores: sequential processing, simultaneous processing, mental-processing composite, achievement, and non-verbal.

The theoretical base for the K-ABC mental-processing scale rests on the assumption that two types of mental functioning exist: sequential functioning, which is characterized by temporal or serial order of stimuli when problems are being solved; and simultaneous processing, which requires a gestalt-like integration of stimuli to solve problems (Kaufman & Kaufman, 1983). The 10 subscales of the mental-processing section (three sequential and seven simultaneous) yield three scores - sequential, simultaneous, and mental-processing composite - thus permitting identification of processing strengths and weaknesses. The tests minimize the role of language skills and include items that transcend the influence of gender and social class (Kaufman & Kaufman).

The K-ABC was standardized on a sample of 2,000 children aged two to 12 years. The sample was stratified for gender, geographic region, parental education, racial-group membership, and community size. The test-retest reliabilities are in the .70s and .80s for the subscales and .80 to .90 for the global scales. The level of correlations with standardized achievement tests and intelligence tests provides concurrent and predictive validity (Kaufman & Kaufman, 1983). The mental-processing composite was used as an outcome measure of information-processing skills.

Developmental Test of Visual-Motor Integration (VMI) measures the integration of visual perception and motor behaviour in children aged four through 17 years (Beery, 1989). This paper-and-pencil test

essentially assesses the child's ability to copy increasingly complex shapes. It was used in this study to supplement the K-ABC mental-processing scales, because the K-ABC does not have a visual expressive processing component to assess children's fine motor abilities. The VMI was standardized on 5,824 children between the ages of two years and six months and 19 years who are representative of the U.S. population as recorded in the 1980 census. The median interrater reliability is .93 and the median test-retest reliability is .81; split-half reliability is .85. There is extensive evidence of concurrent validity with high correlations between chronological age and other tests of visual-motor ability. Predictive validity was established with school achievement (Beery).

Peabody Individual Achievement Test – Revised (PIAT-R) is an individually administered wide-range achievement test. It yields six scores: mathematics, reading recognition, reading comprehension, spelling, general information, and total. The total PIAT-R was used as a measure of academic achievement. The test was standardized on a sample of 1,563 students from geographic locations around the United States and from a wide range of socioeconomic and ethnic backgrounds. Content validity has been established and the PIAT-R has concurrent validity with the Peabody Picture Vocabulary Test. Test-retest reliability ranges from .88 to .98 for the entire test (Markwardt, 1989).

Results

Descriptive statistics and tabulations were run to examine the distribution of scores and to determine whether the data were normally distributed. Because there has been some evidence that high medical risk is associated with social class, Pearson product moment correlations were run between the medical-risk variables and SES in order to determine whether social class and medical risk were confounded in this sample of children (Aylward, 1992). The correlations were small ($< .10$) and there were no significant associations, indicating that medical risk and social class were independent of each other. Measures of association (Pearson product moment correlation) using two-tailed tests of significance were then obtained between the perinatal risk variables (length of stay in the intensive care nursery; number of days on mechanical ventilation; birth weight; intraventricular hemorrhage) and the outcome measures: information-processing skills; visual-motor integration; academic achievement. Correlation coefficients were squared to determine the variance accounted for by each association. Table 2 indicates that none of the measures between the perinatal-risk variables and the outcome measures was significant; the amount of variance accounted for by any of the outcome measures was less than 10%.

Table 2 *Relationship between Medical Risk and Developmental Measures at the End of Grade 3 (N =35)*

Medical Risk	Developmental Measures at End of Grade 3					
	K-ABC (MPC)		VMI		PIAT-R	
	<i>r</i>	Variance Explained	<i>r</i>	Variance Explained	<i>r</i>	Variance Explained
IVH	-.31	10%	-.17	03%	-.29	08%
LICN	.12	01%	.19	04%	.28	08%
NDMV	-.19	04%	-.07	0%	.07	0%
Birth Weight	.12	01%	.03	0%	-.21	04%
K-ABC (MPC) = Kaufman Assessment Battery for Children - Mental-Processing Composite VMI = Beery Test of Visual-Motor Integration PIAT-R = Peabody Individual Achievement Test - Revised IVH = Intraventricular Hemorrhage LICN = Length of Stay in Intensive-Care Nursery NDMV = Number of Days on Mechanical Ventilation						

When preschool and contemporary HOME-Total scores were correlated with the outcome measures, all of the associations between the environmental-process measures and information-processing skills and academic achievement were significant (Table 3). For associations between the home and information-processing skills, the contemporary HOME score accounted for half of the variance in the outcome measure, followed by HOME scores at 12 months (45%) and 24 months (46%). For associations between the HOME scores and academic achievement, HOME scores at 12 and 24 months accounted for over half of the variance, while the contemporary home accounted for one third of the variance. The relationship between the HOME scores and visual-motor integration was significant at only three points in time, 12 and 36 months and contemporary (Table 3).

In order to understand the degree of stability of the children's environment from infancy and preschool to the present, a correlation matrix at seven points in time was constructed using Pearson product moment (Table 4). The correlation coefficients for the relationships between the HOME-Total scores ranged from .58 (HOME at six months with HOME at 24 months) to .90 (HOME at 36 months with HOME at 48 months). The median association was $r = .76$. The environment appears to have had a high degree of stability, with children who enjoyed supportive homes as infants continuing to experience such support through the preschool years and at school age. Likewise, children in less supportive environments as infants continued to experience relative deprivation as preschoolers and at school age.

Table 3 <i>Relationship between Total HOME Score and Developmental Measures at the End of Grade 3 (N =35)</i>						
Deveopmental Measures at End of Grade 3						
HOME Total	K-ABC (MPC)		VMI		PIAT-R	
	<i>r</i>	Variance Explained	<i>r</i>	Variance Explained	<i>r</i>	Variance Explained
HOME 6 Months	.49**	24%	.20	04%	.57**	32%
HOME 12 Months	.67**	45%	.37*	14%	.76**	58%
HOME 24 Months	.68**	46%	.29	08%	.73**	53%
HOME 36 Months	.58**	34%	.37*	14%	.67**	45%
HOME 48 Months	.62**	38%	.21	04%	.67**	45%
HOME 5 Years	.60**	36%	.30	09%	.67**	45%
HOME 9 Years	.72**	51%	.47**	22%	.57**	32%
K-ABC (MPC) = Kaufman Assessment Battery for Children – Mental-Processing Composite VMI = Beery Test of Visual-Motor Integration PIAT-R = Peabody Individual Achievement Test – Revised * < .05 ** < .01						

Table 4 <i>Stability for HOME – Total for Six, 12, 24, 36, 48, 60, and 108 Months (N =35)</i>						
HOME 6 Months	HOME 12 Months	HOME 24 Months	HOME 36 Months	HOME 48 Months	HOME 60 Months	HOME 108 Months
HOME 6 Months	.68*	.58*	.64*	.62*	.62*	.69
HOME 12 Months		.85*	.87*	.82*	.87*	.79*
HOME 24 Months			.78*	.81*	.79*	.60*
HOME 36 Months				.90*	.81*	.72*
HOME 48 Months					.76*	.71*
HOME 60 Months						.63*
HOME 108 Months						1.00
* < .01						

Table 5 *HOME Subscales Associated with Academic Achievement at Nine Years of Age (N = 35)*

HOME Subscales	<i>r</i>
6-Month HOME	
Parental Responsivity	.43**
Acceptance of Child's Behaviour	.29
Organization of Physical and Temporal Environment	.38*
Provision of Appropriate Play Materials	.42*
Parent Involvement with Child	.47**
Variety in Daily Stimulation	.39*
12-Month HOME	
Parental Responsivity	.59**
Acceptance of Child's Behaviour	.35*
Organization of Physical and Temporal Environment	.57**
Provision of Appropriate Play Materials	.47**
Parent Involvement with Child	.70**
Variety in Daily Stimulation	.54**
24-Month HOME	
Parental Responsivity	.65**
Acceptance of Child's Behaviour	.57*
Organization of Physical and Temporal Environment	.46**
Provision of Appropriate Play Materials	.50**
Parent Involvement with Child	.58**
Variety in Daily Stimulation	.51**
36-Month HOME	
Parental Responsivity	.40*
Acceptance of Child's Behaviour	.45**
Organization of Physical and Temporal Environment	.62**
Provision of Appropriate Play Materials	.52**
Parent Involvement with Child	.55**
Variety in Daily Stimulation	.49**
48-Month HOME	
Learning Stimulation	.64**
Language Stimulation	.56**
Physical Environment	.41*
Pride/Affection/Warmth	.25
Academic Stimulation	.38*
Modelling	.62**
Variety in Experience	.57**
Physical Punishment	.42*
* < .05	
** < .01	

(continued on page 89)

Table 5 <i>continued</i>	
HOME Subscales	9-year Academic Achievement
5-Year HOME	
Learning Stimulation	.69**
Language Stimulation	.50**
Physical Environment	.38*
Pride/ Affection/ Warmth	.21
Academic Stimulation	.52**
Modelling	.45**
Variety in Experience	.53**
Physical Punishment	.11
9-Year HOME	
Responsivity	.42*
Encouragement of Maturity	.34*
Emotional Climate	.14
Growth-Fostering Materials	.57**
Active Stimulation	.36*
Family Participation	.55**
Paternal Involvement	.44**
Physical Environment	.32
Academic Achievement = Total Standard Score for Grade of Peabody Individual Achievement Test – Revised * < .05 ** < .01	

In order to understand the distinct characteristics of the environment that support optimal outcome, measures of association (Pearson product monment) between the individual HOME subscales at six, 12, 24, and 36 months and four, five, and nine years and academic achievement at the end of Grade 3 were examined. As expected, there were many significant associations. In addition, individual items in the subscales at each age were examined in order to identify common themes in situations where the name of the subscale changed because the expression of developmental support appropriately changed as the child matured. Table 5 shows the subscale and PIAT-R correlations. The subscales in bold-faced type represent scales contributing to consistent themes. To be identified as a consistent theme, subscales reflecting similar constructs had to be significantly associated with the outcome variable at all data points: six, 12, 24, and 36 months and four, five, and nine years. In Table 5, the subscales in bold-faced type demonstrate five

consistent themes. The first is *parent responsivity*, as expressed verbally (Subscale 1 on the Infancy HOME and the School-Age HOME, and Subscales 1 and 2 on the 48-month and 60-month HOME). The second theme is *parent support for learning*, as expressed in the play scales (Subscale 4 on the Infant HOME), the academic stimulation scales (Subscale 5 on the 48-month and 60-month HOME), and the growth-fostering material scale (Subscale 4 on the School-Age HOME). The third theme is *parent involvement with the child*, expressed in Subscale 5 of the Infancy Scale, Subscale 7 of the School-Age HOME, and Subscale 6 (Modelling) in the 48-month and 60-month Scales. The fourth theme is *exposure to a variety of experiences* expressed in Subscales 6 and 7 of the Birth-to-60-months HOME and the family participation scale (Subscale 6) of the School-Age HOME. Lastly, all the scales (from birth to 60 months and 108 months) that contained items relevant to the *active presence of a father figure* in the household had significant relationships with academic achievement at the end of Grade 3.

Discussion

The lack of measurable impact of the perinatal-risk variables parallels the findings from earlier work with this cohort of children during the preschool years (Schraeder, 1986, 1987; Schraeder et al., 1990; Schraeder, Rappaport, & Courtwright, 1987). While many investigators, including this team, have found that VLBW children as a group are at a relative disadvantage when competing in the classroom (Hack et al., 1992; Lagerstrom, Bremme, Eneroth, & Janson, 1991; Schraeder, Heverly, O'Brien, & Goodman, in press), the etiology of their learning problems cannot be accounted for by specific early medical or biological risk factors. The mechanism for the impact of the biological fact of VLBW on school performance has yet to be explained.

The findings concerning the impact of environmental process variables are congruent with a number of studies that have found that environmental risk indicators or environmental structural measures such as SES have greater influence on academic achievement and cognitive development than birth-weight status (Hack et al., 1992; Ross et al., 1982; Vohr et al., 1989). In this study, the quality of the home environment at several points in time accounted for more than half of the variance in both cognitive processing skills and school achievement.

One area in which the quality of the home environment had a more ambiguous role in outcome is visual-motor integration. There were significant associations with outcome at only three points, 12 and 36

months and contemporary. It may be that some aspects of visual-motor performance are influenced by environmental factors – for instance, parents providing children with crayons and paper for drawing, or parents and children playing games that stress careful attention to geometric properties of objects – while other aspects of visual-motor integration are more likely to be innate, relatively immutable abilities, dependent on a maturational timetable.

Three models of environmental action have been used to explain the way in which processes in the environment influence child development (Bradley, Caldwell, & Rock, 1988). In Model I, derived from paradigms that place primacy on the mother-infant relationship such as attachment and psychoanalytic theory, early relationships with significant others influence future development by serving as the building block for basic trust in the environment. High levels of maternal responsivity and parental attention to, and the availability of, responsive objects provide an opportunity for mastery, which motivates the child for future learning. Model II downplays the effects of the early environment and holds that children's experiences contemporary with the measure of outcome play a large role in the mastery of the outcome measure. Model III postulates the importance of constancy and stability across time. Stable environments buffer children from stress and changes in parental fortunes. In this model, it is not only important that the child be provided with a constant, responsive mother figure early in life, but the parent must engage in activities that are supportive at each developmental stage. Environmental effects are cumulative.

The Bradley et al. (1988) longitudinal study of 42 normal-birth-weight children found support for all three models, with the contemporary measure of the quality of the home environment having the strongest correlation with academic-achievement tests. In this study the home contemporary measure had the highest correlation with cognitive processing skills, but earlier measures of the home environment, particularly those at 12 and 24 months, had higher correlations than the contemporary home with overall academic achievement. This pattern of associations can be explained by another theory of environmental action, which suggests that different developmental outcomes (cognitive processing skills, academic achievement, and visual-motor integration) can be explained by different models of environmental action. Cognitive processing skills might be more sensitive to the effects of the child's home than to school achievement. School achievement may reflect a combination of causative factors such as motivation, work habits, and the quality of the child's school.

Considering the high levels of stability noted in HOME-Total scores for this study, and the variations in degree of correlation over time in both of the outcome measures, support can be mustered for all of the models. However, given what is known about the ongoing dynamic interplay between children and their environments, developmental status probably reflects the history of this interplay and a consistent cumulative effect (Bradley et al., 1994).

The themes identified by this study – parental responsiveness, parental support for learning, parental involvement with the child, and exposure to a variety of experiences – manifested themselves at all stages of development and had moderate to large correlations with academic achievement at the end of the Grade 3. While the themes provide an overall framework for program development, it must be borne in mind that families have their own strengths and weaknesses and any intervention needs to be individually tailored. It may be that some families need help developing responsive interactions, or do well with responsive interactions in infancy but are unable to cope with the busyness and inquisitiveness of the toddler and preschooler and require assistance recognizing these characteristics as positive and important to future learning. Other families may need assistance finding economic and social supports, for they may have the knowledge to provide responsive parenting but be overwhelmed by stress and lack the energy to parent optimally. Some parents may not be able to support their child's learning because they cannot read or do simple figures themselves and may be unable, or may be too ashamed of their situation, to provide the child with appropriate academic supports. Seeking supports for improving parents' own academic skills and helping them to find alternative ways of supporting their children's learning may be the most appropriate intervention in such cases. Other families may need help understanding the importance of exposing children to a variety of experiences. Many of the families in this study lived in or near a city rich in museums and cultural activities but did not expose their children to these attractions because of their social isolation and fear of crime. This situation is not confined to subjects in low SES homes, but is also characteristic of many families who live in middle-class suburbs. Yet variety of experience, expressed by taking the preschooler to the dry cleaner or the grocery store, or by taking the eight-year-old to the "dinosaur" museum, has strong associations with academic achievement.

It is clear from this study that VLBW is not just a problem of medical risk. Interventions aimed at decreasing the academic and social hazards of low-birth-weight children longitudinally should take place

in the community and in the home. Analysis of HOME data over nine years suggests what some of these interventions could encompass. While we have little information about the effectiveness of interventions for families of VLBW children and the characteristics of families who would benefit from the interventions (Bradley et al., 1994), this study is a small step in delineating what those interventions might be.

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Developmental versus Conventional Care: A Comparison of Clinical Outcomes for Very Low Birth Weight Infants

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L'objectif de la présente recherche était de décrire le profil clinique des nouveaux-nés dont le poids à la naissance était extrêmement faible alors qu'on leur prodiguait des soins standardisés ou des soins individualisés en fonction du développement durant leur hospitalisation, et de déterminer si les interventions individualisées en fonction du développement ont été appropriées. Une étude (par phase décalé) auprès de 124 prématurés a montré que, même s'il n'existe pas de différence importante pour ce qui concerne les résultats cliniques individuels, les soins individualisés en fonction du développement ont eu à la longue un effet significatif sur la stabilité physiologique de l'enfant. Tous les nourrissons à qui on prodiguait des interventions individualisées en fonction du développement ont bénéficié, avec fréquence variable, de soins individualisés en fonction du développement.

The purpose of this research was to describe the clinical profile of very low birth weight (VLBW) infants receiving conventional versus developmental care during their hospitalization and to determine the appropriateness of developmental-care interventions. A phase-lag study with 124 preterm infants indicated that although there were no significant differences in individual clinical outcomes, developmental care had a significant effect on the physiologic stability of the infant over time. Developmental interventions were used for all infants receiving the developmental-care intervention, with varying frequency.

Enormous financial and technological resources have been allocated for neonatal intensive care, resulting in a dramatic improvement in mortality and morbidity for the very low birth weight (VLBW) infant. This improvement, however, has been tempered by the emergence of subtle long-term developmental delays in learning, academic achievement, visual-motor integration, and language performance, and in behav-

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itorial difficulties (Hack et al., 1994; Ornstein, Ohlsson, Edmonds, & Asztalos, 1991). These delays may be the result of intrauterine insult prior to the onset of labour (Low, Robertson, & Simpson, 1989; Low, Simpson, & Ramsey, 1992) or the result of the extrauterine environment. Recent documentation indicates that there is a 50% incidence of cognitive dysfunction at school age among neurologically intact VLBW survivors. Careful attention to the nature and quality of care of the VLBW infant in the neonatal intensive-care unit (NICU) can optimize the quality of survival and positive developmental outcomes (Hack et al., 1991).

An individualized, developmentally sensitive approach to neonatal care was proposed more than a decade ago to enhance clinical outcomes and the developmental potential of VLBW infants and their families (Als, 1984). Investigators have reported that VLBW infants who received developmental care demonstrated improved clinical and developmental outcomes (Als et al., 1986; Als et al., 1994; Becker, Grunwald, Moorman, & Stuhr, 1991, 1993; Buehler, Als, Duffy, McAnulty, & Liederman, 1995; Fleisher et al., 1995). However, a number of methodologic issues have been raised (Garland, 1995; Lacy, 1995; Ohlsson, 1995; Saigal & Streiner, 1995). In addition, the physiologic stability of the NICU infant and the appropriateness of developmental-care interventions have not been thoroughly investigated. The purpose of this research was (a) to compare clinical outcomes (including severity of illness) of VLBW infants receiving conventional versus developmental care during the NICU stay, and (b) to determine the appropriateness of developmental-care interventions.

Theoretical Framework

Als's (1982) Synactive Theory of Development incorporates ethological and behavioural theory and physiologic principles to develop a framework for understanding medical and behavioural outcomes. The infant is viewed as a dynamic organism that continually strives for equilibrium and is in constant interaction with the environment. The developmental approach to care envisions infants as active participants in their own developmental trajectories, supported by the ongoing co-regulation process of infant and parent development. For preterm infants who are unexpectedly removed from the intrauterine environment and its complex co-regulatory mechanisms, it is extremely important that NICU care is supportive of the realignment and co-regulation of the newborn and his family.

Literature Review

Developmental care is an individualized-care approach that uses systematic behavioural observations (Newborn Individualized Developmental Care and Assessment Program – Als, 1986, 1992) and a formal evaluation of infant behaviour (Assessment of Fullterm and Preterm Infants' Behaviour – Als, Lester, Tronick, & Brazelton, 1982; Als, Duffy, & McAnulty, 1988). The results of these observations and evaluations provide the basis for an individualized plan of care to support the infant, which involves (a) structuring the physical environment to reduce light and noise levels; (b) minimal handling, clustering of care, time-out, and use of a pacifier; (c) bundling, nesting, and containment; and (d) flexion of infant extremities, hand-to-mouth, and prone/side positioning (Als, 1984, 1992).

The evidence supporting positive clinical outcomes associated with developmental care for VLBW infants has been steadily accumulating (Als et al., 1986; Als et al., 1994; Becker et al., 1991, 1993; Buehler et al., 1995; Fleisher et al., 1995). In phase-lag studies (Als et al., 1986; Becker et al., 1991, 1993) and a randomized controlled trial (Als et al., 1994), VLBW infants who received developmental care demonstrated more optimal respiratory and feeding status, lower levels of morbidity, shorter hospital stay, and improved behavioural organization. In Als's most recent study (Als et al., 1994), infants followed up to nine months who had received developmental care showed improved neurodevelopmental outcomes over those who had not. Buehler et al. (1995) also report that preterm infants who received developmental care showed behavioural and electrophysiologic performances comparable to full-term infants at two weeks after the expected due date, whereas infants in a control group performed significantly less well. Fleisher et al. (1995) report more organized performance in motor-system function, state regulation, interactive capabilities, and ability to self-regulate at 42 weeks postconceptual age.

Although the differences between infants receiving developmental care and those receiving conventional care on reported clinical outcomes and costs are impressive, the research often suffers from methodologic inadequacies. The studies have been criticized for their sample size, sample selection bias, complexity of observations, method of allocation concealment, over-generalization of results, and for using a large number of dependent variables, with inappropriate analyses (Garland, 1995; Lacy, 1995; Lacy & Ohlsson, 1993; Ohlsson, 1995; Saigal & Streiner, 1995).

In the first study by Als et al. (1986), only 16 of the 43 infants eligible for the study were included. The Becker et al. (1991, 1993) study included 21 control and 24 study infants. Studies by Fleisher et al. (1995) and Buehler et al. (1995) had no more than 12 infants per experimental or control group. These small numbers may have allowed the introduction of unknown biases and limited generalization of the results. In the Als et al. (1986) and Becker et al. (1991, 1993) studies, the inclusion criteria favoured the experimental group according to infant gestational age, mean birth weight, and mean Apgar scores. Only a few studies were conducted following the widespread use of surfactant, and therefore the results may not be generalizable to present-day NICUs. Several studies used complex data-collection measures without the benefit of multivariate analyses or adjustment for multiple comparisons.

Many studies employed phase-lag designs that precluded blinding or adequate concealment of the treatment groups. Despite claims regarding large cost savings, there is little detail on the calculation of direct hospital charges or indirect costs to hospitals, to other health-care institutions where infants are transferred, or to families.

None of the published studies adequately addresses physiologic stability of VLBW infants or the appropriateness of developmental-care interventions. Severity of illness as a consequence of NICU is often directly related to the functional status of preterm infants as measured by physiologic stability and the potential for comorbidity and/or complications (Petryshen & Stevens, 1995). Physiologic stability is also a useful measurement for providing classifications for evaluating the degree of physiologic stress in preterm infants (Richardson, Gray, McCormick, Workman, & Goldman, 1993). Data on physiologic stability could reflect the amelioration of stress for infants receiving both developmental and conventional NICU care and, as such, could be considered an indicator of quality of life in this population.

Based on these inadequacies, the American Academy of Pediatrics Committee on the Fetus and Newborn was challenged to evaluate the developmentally sensitive approach to care and make recommendations regarding the appropriateness of its use in the NICU (Merenstein, 1994). The Canadian Pediatric Society Committee on the Fetus and Newborn has also taken on this challenge (Abbott Laboratories, 1994).

Methods

Setting and Sample

The study was conducted at Toronto's Mount Sinai Hospital (MSH), a university-affiliated teaching hospital with a 50-bed Level 11 and Level 111 NICU where the care-delivery model is primary nursing. Of the 130 infants admitted to the study over an 18-month period, 65 received conventional care and 65 received developmental care. Infants were eligible to participate in the study if they were between 750 and 1,500 grams at birth, an appropriate weight for gestational age at birth (as determined by an antenatal ultrasound and Dubowitz assessment), and free of chromosomal and/or other major genetic anomalies and/or congenital infections. In the case of multiple births, the first-born infant was entered into the study.

Sample-Size Estimation

The sample-size estimate was consistent with that reported in other developmental-care research conducted by Als et al. (1986) and Becker et al. (1991, 1993). Oxygen saturation, rate of weight gain, and length of stay were used to estimate the effect size ($\alpha .05$, with 80% power). For the three outcome variables, the most conservative sample-size requirement was for the variable oxygen saturation, whereby a sample size of 63 subjects per group was required to detect a significant difference at the 5% level (Kramer, 1988). As a very low level of refusal was anticipated, 65 subjects per group were entered into the study.

Data-Collection Procedure

A comparative (phase-lag) study design was used to compare clinical outcomes of infants receiving conventional versus developmental care. A clinical trial randomizing infants to conventional versus developmental care was not feasible, because the NICU environment employs an open concept. Conventional care would be contaminated with nurses implementing the developmental-care interventions. Ethics approval for this study was obtained from the Research Ethics Board. Eligible infants were identified by the clinical nurse specialist, the study was explained to the parents, and the parents were asked to give their written consent. Data on clinical outcomes and the frequency and type of developmental-care interventions were collected by the research nurse within the first 72 hours of the infant's birth, as well as on days 7, 14, 21, 28, and 35 of the hospital stay. Clinical and demographic information was abstracted from the infant's medical record.

Data were collected for the infants in the conventional-care group during an eight-month period prior to the implementation of developmental care. Developmental care was implemented and a three-month integration period was left before data collection was resumed. Data for the developmental-care group were collected during a five-month period eight months after developmental care had been implemented.

Conventional-Care and Developmental-Care Groups

Conventional care in this setting involved primary nursing by experienced neonatal nurses, standardized care plans, and unadjusted lighting and noise levels. Nurses did not receive any developmental-care training prior to or during data collection. *Developmental care* involved experienced neonatal nurses trained in developmental care, individualized patient-care plans, developmental-care interventions (such as bundling, positioning, and containment), and decreased lighting and noise levels. All nurses on the unit received a three-day orientation to developmental care and six nurses were trained and certified as developmental-care specialists. Repeated in-service education was offered to nurses and physicians. Reduced lighting levels were achieved by using isolette covers and dimming overhead lights. Reduced noise levels were achieved by lowering the volume of the overhead paging system and substituting flashing lights for the ringing in the fire-alarm system. These changes were implemented following discussions with external consultants.

It is possible that the conventional-care group was contaminated by the use of developmental-care interventions (such as bundling, positioning, and containment) on the part of experienced nurses who had read or heard about developmental care. However, the impact was thought to be minimal considering the individualized care plans and additional developmental-care interventions such as lighting and noise reductions, time-out, clustering of care, and increased interactions with families. No attempt had been made, prior to this study, to introduce developmental care into the NICU or to formally educate nurses in this approach to care.

Measures

The *Physiologic Stability Index (PSI)* (Georgieff, Mills, & Bhatt, 1989) was used to assess the level of physiologic instability in critically ill infants. By quantifying physiologic instability, the PSI sub-scores provided an overall assessment of the severity of the infant's illness. The

original PSI, developed to assess severity of illness in critically ill pediatric patients, consisted of 34 variables from seven physiologic systems, including cardiovascular, respiratory, and neurological (Yeh, Pollack, Ruttimann, Holbrook, & Fields, 1984). The degree of abnormality (during the previous 24 hours) of each variable (i.e., heart rate, respiratory rate, blood pressure) was assigned a score from 0 to 5 reflecting the clinical importance of the derangements. Content validity was established by using the clinical judgement of pediatric intensivists to score the abnormality of the observed measurements. Criterion validity was determined by comparing the PSI with the Clinical Classification System (Civetta, 1973) and the Therapeutic Intervention Scoring System (Cullen, Civetta, Briggs, & Ferrara, 1974; Keene & Cullen, 1983). Construct validity was demonstrated by comparing PSI scores with hospital mortality rates and between diverse groups. There were no reports on the measure's reliability. The original PSI (Yeh et al.) was modified by Georgieff et al. to reflect neonatal physiology. In re-establishing criterion and construct validity for the modified 26-item measure, the PSI scores correlated significantly with the Therapeutic Intervention Scoring System (TISS) (Cullen et al.; Keene & Cullen) ($r = .75, p < .001$) and Nursing Utilization Management Intervention System classifications ($r = .62, p < .001$). The modified form of the PSI for premature infants was pretested and then used in this study.

The NICU Daily Patient Record, a standard form from the study setting, was used to record information on the number of days on oxygen and on the ventilator and growth measures (weight and head circumference). Data on the incidence and frequency of developmental-care interventions were also recorded by the developmental-care specialist or the bedside nurse. This record was kept at the bedside of each infant in the study.

Data Reduction and Management

All data were recorded directly on the data-collection measures and stored in a locked drawer in the office of the research nurse. Confidentiality was maintained through the use of numerical codes. A master list of study codes and names of participating infants was stored in the office of one of the co-principal investigators. The master list was destroyed at the end of the study, but the coded data were kept and could be retrieved through the medical records department for future analyses, if so desired. All data were entered on the SPSS:PC software program by a trained data-entry clerk, and summary scores were computed for each outcome variable, including the PSI.

Results

Data were analyzed using (a) descriptive statistics to describe the study sample, distribution of the data, and frequency of developmental-care interventions, and (b) parametric statistics (unpaired *t*-tests and logistical regression) to detect significant differences between the groups and to determine the effect of the study intervention over time.

Descriptive Characteristics of the Groups

A total of 130 infants (65 per group) were entered into the study. There were no refusals. Of the 130 infants, 4/65 infants in the conventional-care group and 2/65 infants in the developmental-care group died prior to day 3 of life, leaving 61 and 63 infants, respectively, in the conventional-care and developmental-care groups for the analyses.

Mean gestational age at birth for the conventional-care group was 28.43 weeks (*SD* 2.28), for the developmental-care group 28.56 weeks (*SD* 1.73). Mean birth weight for the conventional-care group was 1,078 grams (*SD* 224), for the developmental-care group 1,140 grams (*SD* 202). Mean head circumference at birth for the conventional-care group was 26.07 cm (*SD* 1.88), for the developmental-care group 26.58 cm (*SD* 1.72). There were no significant differences between the two groups for gestational age at birth ($t = -0.36, p < .73$), birth weight ($t = -0.62, p < .11$), or birth head circumference ($t = -1.50, p < .14$).

Incidence and Frequency of Developmental-Care Interventions

The developmental-care interventions were summarized for each infant at the end of each week of life (days 7, 14, 21, 28, and 35), to gain an understanding about which interventions were used most frequently during hospitalization. Interventions were summarized into three categories: caregiving (minimal handling, clustering of care, time-out, use of pacifier); containment (bundling, nesting, containment with hands); and positioning (flexion, hand-to-mouth positioning, prone- and side-lying, foot and side rolls). The percentage of infants in the developmental-care group who received each intervention as recorded daily on the NICU Daily Record at 7, 14, 21, 28, and 35 days is reported in Table 1.

During caregiving, all developmental-care interventions described by Als were used. Minimal handling and clustering of care were most

evident in the earlier weeks of hospitalization. Time-out from being handled and use of a pacifier as a developmental intervention were used throughout hospitalization. Approximately 50% of the infants were given a pacifier during their first 35 days of life. Bundling and containment were used substantially; nesting was used less often. Flexion of the infant's extremities and positioning of hand to mouth was an important developmental approach. Infants were often placed in the prone/side position, with occasional use of foot and side rolls.

Table 1 *Percentage of Infants Receiving Developmental-Care Interventions during the First 35 Days of Hospitalization*

	Day				
	7	14	21	28	35
Developmental-Care Interventions	(n = 63)	(n = 56)	(n = 50)	(n = 44)	(n = 39)
Caregiving					
Minimal handling	44%	20%	8%	7%	13%
Clustering of care	33%	20%	18%	11%	13%
Time-out	29%	34%	28%	36%	21%
Pacifier	44%	50%	56%	48%	51%
Containment					
Bundling	41%	55%	44%	55%	41%
Nesting	24%	21%	16%	18%	5%
With hands	67%	61%	50%	50%	31%
Positioning					
Flexion	73%	71%	54%	57%	41%
Hand to mouth	25%	30%	22%	20%	23%
Prone & side lying	68%	70%	68%	64%	26%
Foot & side rolls	17%	21%	26%	23%	5%

Comparison of Clinical Outcomes between Groups

Physiologic Instability Index (PSI) (Georgieff et al., 1989) scores were calculated weekly to assess the level of physiologic instability in critically ill infants. There were no significant differences using multiple comparisons (*t*-tests for independent groups) between the conventional-care and developmental-care groups in PSI scores at admission and days 7, 14, 21, 28, and 35. However, lower mean PSI scores were

found in the developmental-care group at all points except day 35 (Table 2). The overall effect of group and time on PSI was examined using repeated measures analysis of variance (RMANOVA). However, there was insufficient power, due to the declining sample size as infants were discharged or transferred prior to day 35, to detect any significant effects with this analysis.

Table 2 *Mean Scores on PSI by Care Group and Day*

Day	Group		<i>t</i>	<i>p</i>
	Conventional Care	Developmental Care		
Admission				
<i>M</i>	17.25	16.21	0.78	.44
<i>SD</i>	(7.07)	(7.81)		
<i>n</i>	61	63		
Day 7				
<i>M</i>	13.82	12.03	1.25	.22
<i>SD</i>	(7.60)	(8.29)		
<i>n</i>	61	63		
Day 14				
<i>M</i>	13.32	11.09	1.52	.13
<i>SD</i>	(7.95)	(7.54)		
<i>n</i>	56	56		
Day 21				
<i>M</i>	12.43	11.74	0.43	.67
<i>SD</i>	(8.05)	(8.02)		
<i>n</i>	51	50		
Day 28				
<i>M</i>	12.14	9.68	1.42	.16
<i>SD</i>	(7.92)	(8.24)		
<i>n</i>	44	44		
Day 35				
<i>M</i>	9.49	10.00	-0.30	.77
<i>SD</i>	(7.66)	(7.61)		
<i>n</i>	39	39		
Note: Higher scores on the PSI indicate greater infant instability.				

While there were no significant effects of treatment group on PSI scores, any potential benefits of developmental care, as evidenced by the overall pattern of means on days 7 through 28, may have been obscured by the relatively high degree of variability in PSI scores within each group. Subsequent exploratory analyses revealed that the distribution of PSI scores was bimodal, suggesting that infants might be better classified as high or low in physiologic stability. The PSI scores were recoded as a dichotomous variable, and the data for days 7 through 28 were re-analyzed using logistic regression. Infants who received a PSI score of 10 or less were classified as stable, while those who received a PSI score of 11 or greater were classified as unstable. This 10-11 split represents the point at which there was a clear break in this distribution, rather than an arbitrary mid-point median. As shown in Table 3, logistic regression analysis revealed a significant effect of treatment day on PSI and also a significant effect of group, such that infants who received development care were more likely to be classified as high in physiologic stability (lower PSI scores) during each week of their hospitalization as compared with infants who received conventional care.

Table 3 <i>Summary Table for Hierarchical Logistic Regression of PSI on Group and Day of Hospitalization</i>							
Variable	<i>b</i>	<i>se</i>	Wald	<i>df</i>	<i>p</i>	χ^2	<i>df</i>
Step One: Main Effects Model						8.97	2
Constant	0.707	0.331	4.559	1	.033		
Group	-0.433	0.197	4.859	1	.028		
Time	-0.182	0.089	4.559	1	.033		
Step Two: Interaction Model						0.15	1
Constant	0.821	0.447	3.381	1	.067		
Group	-0.662	0.628	1.111	1	.292		
Time	-0.216	0.126	2.938	1	.087		
Group* Time	0.068	0.178	0.148	1	.701		
Note: PSI was coded as a classification variable (0=stable, 1=unstable). Intervention group was also a classification variable (0=conventional care, 1=developmental care).							

Table 4 Mean Scores on Growth Measures by Conventional/Care Group and Day of Hospitalization

Day	Weight (gr)				Head Circumference (cm)			
	Group		<i>t</i>	<i>p</i>	Group		<i>t</i>	<i>p</i>
	Conventional Care	Developmental Care			Conventional Care	Developmental Care		
Day 7 M SD <i>n</i>	1008.61 (233.32) 61	1050.32 (218.53) 63	-1.03	.31	26.07 (2.04) 54	26.82 (1.67) 55	-2.10	.04
Day 14 M SD <i>n</i>	1102.81 (250.59) 57	1136.95 (223.65) 56	-0.76	.45	26.85 (2.11) 54	27.29 (1.71) 52	-1.18	.25
Day 21 M SD <i>n</i>	1165.70 (265.02) 50	1220.40 (252.69) 50	-1.06	.30	27.49 (1.99) 45	27.82 (1.77) 47	-0.84	.41
Day 28 M SD <i>n</i>	1244.89 (277.27) 44	1319.55 (295.62) 44	-1.22	.23	28.06 (2.05) 40	28.66 (1.99) 41	-1.33	.19
Day 35 M SD <i>n</i>	1338.03 (291.89) 38	1429.87 (318.29) 39	-1.32	.20	28.34 (2.15) 38	29.57 (1.91) 39	-2.42	.02

Four clinical outcomes (number of days on oxygen, number of days on the ventilator, weight, head circumference) were compared in the two groups. The mean number of days on oxygen in the conventional-care group was 10.21 (*SD* 12.88), in the developmental-care group, 7.38 (*SD* 10.50). The mean number of days on the ventilator in the conventional-care group was 14.51 (*SD* 13.34), in the developmental-care group, 12.77 (*SD* 14.09). There were no significant differences between the two groups of infants in number of days on oxygen ($t = 1.33, p < .19$) or on the ventilator ($t = 0.70, p < .49$). There was no difference in weight gain between the groups at any data-collection point. However, infants in the developmental-care group displayed a significantly greater head circumference one week after birth ($t = -2.10, p < .04$) and at the end of the study, on day 35 ($t = -2.42, p < .02$) (Table 4).

Discussion

Health professionals in NICUs throughout North America are advocating widespread implementation of developmental care in response to promising reports of its effectiveness. Although there are reported improvements in clinical outcomes, such as days on the ventilator, days on oxygen, and length of stay in the NICU, there has been little research into whether developmental care improves the infant's growth, quality of life, and physiologic stability. There is also a paucity of research on the appropriateness of implementing these interventions for VLBW infants during their hospital stay.

No differences in the clinical outcomes of weight gain, days on the ventilator, or days on oxygen were found in this study. This finding is inconsistent with the published results of several other studies, which report fewer days on the ventilator and on oxygen and tolerance of full breast or bottle feeding. The inconsistency in findings may be due to methodologic inadequacies in the other studies, as discussed in the literature review.

The phase-lag design in the early Als study (1986), the Becker study (1991, 1993), and the present study is also problematic in that there is no control for historical extraneous variables in the settings, which may account for the reported differences between the two groups. For example, because current economic restraints demand shorter hospital stays, it is not possible to compare length of stay in the present study. Length of stay is also problematic in that it is highly susceptible to the discharge practices of physicians, the space needs of the unit, and the discharge and transfer policies of the unit. The RCT design is also problematic when randomization of developmental care takes place within

the same clinical setting as conventional care. Contamination between groups is impossible to control in circumstances of environmental interventions and shared caregivers. In order to determine the effect of developmental care on the infant, randomization of similar NICU settings must be carried out. Even then, the sites must be matched to allow for reasonable comparison. In light of the difficulty (and expense) of this design, the clinical profile of the infant at birth and throughout the study allows for statistical control of likely extraneous effects.

In this study, there was a significant difference in severity of illness when infants were classified on the PSI as stable or unstable. It is conceptually feasible that severity of illness takes into account the individual differences in clinical outcomes reported in other studies, even though they were not evident as individual clinical outcomes in this study. These results suggest that developmental care is effective, and, most importantly, that it is effective in improving the physiologic stability or quality of life of the infant. When these differences are translated into caregiver time and NICU costs, substantial benefits may be realized. An analysis of costs was beyond the scope of this paper but is addressed elsewhere (Petryshen, Stevens, Hawkins, & Stewart, submitted).

Finally, this study provides some evidence about the most frequently used developmental-care interventions for VLBW infants in their trajectory through the NICU. Although all interventions were used throughout an infant's hospitalization, there was a pattern to how particular interventions were employed. Because nurses who developed the care plans for these infants had been NIDCAP trained, it was assumed that interventions were proposed and implemented based on observation of and response to infant cues. Those interventions that supported the integrity of infant boundaries (nesting, flexion, containment), maintained infant state equilibrium (minimal handling, clustering of care), and promoted infant coping (containment with hands, pacifier) were most frequently implemented in the first weeks of the infant's stay in the NICU. Although nurses continued to implement these interventions throughout the infant's stay in the NICU, the frequency of the interventions decreased over time as they became less appropriate. Other interventions (time-out, pacifier, bundling) were implemented consistently and may have provided comfort, security, and a sense of equilibrium to the vulnerable VLBW infant in a chaotic environment.

Conclusions

Developmental care had a positive effect on the physiologic stability and one growth outcome (head circumference) of the VLBW infants in this study. This effect is conceptually consistent with the improvement in individual clinical outcomes reported in the literature. Developmental care had no effect on other individual clinical outcomes (e.g., days on the ventilator, days on oxygen, weight gain) in this study. The frequent use of developmental-care interventions by nurses caring for VLBW infants within the NICU setting supports the appropriateness of this individualized type of care.

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Predictors of Success on the Canadian Nurses Association Testing Service (CNATS) Examination

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La présente étude rétrospective a observé la relation entre les variables d'admission sélectionnée et les performances pendant les études par rapport à la réussite aux examens du *Canadian Nurses Association Testing Service (CNATS)* de 114 étudiants admis de l'école secondaire directement à un baccalauréat en sciences infirmières au Canada, programme intégré en quatre ans axé sur l'apprentissage par problèmes. On a analysé les données en utilisant des régressions hiérarchiques. On a examiné dans la première phase de régression une série de notes du secondaire (*Ontario Academic Credits ou OAC*) utilisées pour le calcul des moyennes d'admission à l'université et leur capacité à prévoir la performance quant au CNATS. On a constaté que les meilleures variables prédictives étaient les OAC en anglais, puis les OAC en chimie et la moyenne des admissions obtenue par les OAC dans d'autres matières. On a examiné dans la deuxième phase de régression, les notes obtenues au cours des études comme variables prédictives éventuelles des résultats au CNATS. La meilleure variable prédictive s'est révélée être celle des sciences fondamentales, suivie de celle de la méthodologie de la recherche, les concepts en sciences infirmières (1^{er} niveau), une moyenne en apprentissage par problèmes des sciences infirmières et une moyenne en pratique clinique. Les résultats appuient l'utilisation continue de l'anglais et de la chimie comme critères d'admission. Les cours de sciences fondamentales et ceux de première année en sciences infirmières sont également apparus comme des variables prédictives importantes sur le plan statistique de la réussite à l'examen pour l'obtention du permis d'exercice.

This retrospective study examined the relationship of selected admissions variables and in-course performance to success in the Canadian Nurses Association Testing Service (CNATS) examinations of 114 students admitted directly from secondary school to a four-year integrated, problem-based learning (PBL) baccalaureate nursing program in Canada. Data were analyzed using two separate hierarchical stepwise regression equations. The first equation examined a set of secondary school grades (Ontario Academic Credits, or OACs) used to calculate university admission averages and their ability to predict CNATS performance. OAC English was found to be the best predictor, followed by OAC chemistry and the admission average obtained on other OAC subjects. The second regression equation looked at in-course grades as potential predictors of CNATS scores. The basic sciences variable proved to be the best predictor, followed by research methodology, first-year Nursing Concepts I, a problem-based nursing average, and a clinical practice average. Findings support the continued use of English and chemistry as admission criteria. The basic sciences courses and first-year nursing courses also emerged as statistically significant predictors of licensure examination success.

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The literature is replete with reports of studies into the variables that predict success in professional nursing licensure examinations. Some studies have explored admissions criteria and their relationship to R.N. examination results (Jacono, Keehn, & Corrigan, 1987); others have focused on variables within the nursing program itself for indicators that would predict success on the R.N. examinations (Heupel, 1994; Waterhouse, Carroll, & Beeman, 1993); yet others have studied variables across the spectrum, from admission to courses within the nursing program and their relationship to R.N. outcomes (Froman & Owen, 1989; Wall, Miller, & Widerquist, 1993). In all these studies, multiple variables appear to be the predictors of success.

The present retrospective study was conducted as a component of ongoing research to determine the validity of the selection criteria and the in-course performance of post-high school Ontario Academic Credit (OAC) entrants to the McMaster University B.Sc.N. program as predictors of success on the Canadian Nurses Association Testing Service (CNATS) examinations.

B.Sc.N. Curriculum

The four-year curriculum of the B.Sc.N. program comprises nursing theory and clinical courses, health sciences courses in the basic sciences, research methodology, critical appraisal of literature, and determinants of health, as well as electives. While clinical course work in this program is not unlike that of other nursing programs, theory content is presented in problem-based learning (PBL) format, in small-group tutorials, rather than in content-specific courses. In the PBL format, groups of six to 10 students work with a faculty tutor to explore a variety of health-care scenarios, with the aim of identifying learning and health-care issues in a holistic, client-centred fashion.

Study Design

A two-phase correlational study design was used to test the relationships between:

1. The criterion variable of student performance on the CNATS examination and the predictor variables of admissions criteria (OAC English, OAC chemistry, and overall nursing admission average).
2. The criterion variable of student performance on the CNATS and in-course performance in the B.Sc.N. program as measured by: nursing average, basic science average, health sciences average, PBL average, and clinical practice average.

Outcome Variable

The CNATS examination is the national professional nursing licensure examination, written by graduates of both diploma and baccalaureate programs. The passing score is 350 (out of a possible 700), and the national failure rate is standardized and set at 4% annually.

Predictor Variables

I. Admission criteria. Admission to the four-year B.Sc.N. program for secondary school applicants is based on a nursing admissions average calculated on grades obtained in six subject areas: OAC English, OAC chemistry, one OAC mathematics (i.e., calculus, geometry, or finite math), one additional OAC science (i.e., physics or biology), and two additional OACs (best two subjects in addition to those listed above). For the purpose of this study, a new nursing admission average (NEWADMAV) was recalculated for all students, based on the final grades obtained in four required OAC subject areas excluding English and chemistry. This permitted analysis of OAC English, OAC chemistry, and NEWADMAV as three independent variables, which were then examined to determine their contribution to the variance in CNATS scores.

II. In-course performance (Curriculum Variables). For purposes of analysis, the curriculum was conceptualized as having four "content areas," and averages were calculated using final grades in basic sciences (BASICSCI), health sciences (HLTHSCIAV), PBL, and clinical nursing practice (CLINICAL), excluding the level-four courses. In 1992-93 a pass/fail system was adopted for all clinical courses, thus eliminating a range of individual grades. An exit variable called "nursing average" (REVNSGAV) was calculated based on final grades in all the nursing courses for the four years of the program.

Subjects

Between 1987 and 1989, 149 OAC applicants entered the first year of the B.Sc.N. program. Of these, 114 successfully completed the program four years later, wrote the CNATS examinations within the time frame of the study (i.e., September 1987 to June 1993), and gave permission for the program to access their CNATS scores. Most subjects were females (only two OAC entrants were males during the study years) and between the ages of 17 and 20 at the time of admission to the program.

Data Analysis

Admission variables, in-course marks, and CNATS scores of the 114 subjects were analyzed using both descriptive and inferential statistics.

Findings

CNATS scores ranged from 131 to 690. Nine students (7.8%) received a failing grade (i.e., <350): two in 1991 (5.6%), two in 1992 (5.3%), and five in 1993 (12.5%). While the admissions grades and averages of unsuccessful students were not different from the overall sample, examination of in-course grades did identify the fact that the majority of this group achieved grades below the mean in all courses other than the fourth-year PBL tutorial and the final clinical course of the third year.

The university admission average cut-off ranged from 82.5% in 1987 to 80.0% in 1989. The NEWADMAV calculated for this study, based on math and science grades, resulted in a lower minimum, of 74.5%, for the overall sample; the range for students who subsequently failed the CNATS was 78.3% to 89.0%.

Multiple regression analysis with CNATS as the dependent variable and the academic admission criteria as the independent variables indicated that OAC English was the best predictor of performance on the CNATS, contributing 3.7% of the variance, followed by OAC chemistry, providing an additional 6.6%, and then the nursing admission average, providing an additional 4.2%, for a total of 14.5%.

To examine in-course performance, a forward stepwise regression procedure was used. The BASICSCI was found to be the strongest predictor of success on CNATS, $F(1,112) = 21.15$, $p = .000$, followed by the HLTHSCIAV, PBL, and then CLINICAL averages. While the first-year nursing course (Nursing Concepts I) includes both clinical and PBL components, a stronger association was found by including it in the PBL component and excluding it from the clinical component.

Table 1 *Step-by-Step Hierarchical Regression Comparing Admission Criteria and CNATS Scores (N=114)*

Step	Variable	Partial F	Significance	Variance (R ²)
1.	OAC English	$dF(1,109)$ 4.27	$p = .04$	3.7%
2.	OAC chemistry	$dF(2,108)$ 7.93	$p = .005$	10.3%
3.	NEWADMAV	$dF(3,107)$ 5.30	$p = .02$	14.5%

After determining the best subset of positive predictor variables (again, using a forward stepwise regression analysis), the decision was made to return to an individual-course approach. With fewer variables left to consider, the subject-to-variable ratio was increased. A model was sought that would contribute an R^2 value of at least 30% at the final step, which would indicate significant prediction (Norman & Streiner, 1994). Three courses that were found to have a slightly negative predictive value and two courses that neither added to nor detracted from the regression were dropped from the analysis. Despite these changes to the original design, the four curriculum variables of basic sciences, health sciences, PBL, and clinical components all continued to be represented in the equation. The best set of indicators, based on a hierarchical stepwise regression model, is illustrated in Table 2.

Table 2 *Results of Stepwise Multiple Regression Tests for Predicting CNATS (N=114)*

Step	Variable (Individual Courses)	F	Significance	(R^2)
1.	Human Biological Science I Human Biological Science II	$dF(2,111) = 11.91$	$p = .0000$	17.6%
2.	Introduction to the Research Process	$dF(3,110) = 3.05$	$p = .08$	19.9%
3.	Nursing Concepts Year 1 (PBL)	$dF(4,109) = 6.04$	$p = .01$	24.1%
4.	Nursing Concepts Year 2 (PBL) Nursing Concepts Year 3 (PBL) Nursing Concepts Year 4 (PBL)	$dF(7,106) = 1.84$	$p = .14$	27.8%
5.	Guided Nursing Practice I (Clinical) Guided Nursing Practice II (Clinical) Guided Nursing Practice III (Clinical)	$dF(10,103) = 1.14$	$p = .33$	30.2%

Limitations

One of the concerns regarding PBL is that the interrater reliability of grades among tutors may be low. In an effort to address this concern, detailed course objectives and teaching guides are prepared and tutor meetings are held frequently.

Lack of comparability of grades across secondary schools is acknowledged as a shortcoming. The School of Nursing at present does not weight OAC grades based on reputation of schools, so some inaccuracies may be inherent in comparing the university admission averages of students from many different high schools.

Lack of independence among predictor variables is an ongoing problem in predictive validity research. When those variables serve as selection criteria for admission, the problem is further complicated (Higgs, 1984).

Conclusions

The present study was faced with the challenge of identifying predictive relationships in an integrated, problem-based, small-group, self-directed curriculum in which the content of any given course was not clearly discrete from that of other courses. Students entering any program will bring with them many personal attributes, in addition to their academic qualifications, which will affect their learning within and beyond the formal curriculum. The wide range of electives that students choose also will affect their learning.

The findings of this study cannot be generalized to programs that include other admission variables and/or that have different curricula. Previously published studies report that graduates of PBL curricula may not perform as well as graduates of more traditional programs (Albanese & Mitchell, 1993; Vernon & Blake, 1993). However, measures such as licensure examinations show that nearly all the graduates of the B.Sc.N. program at McMaster are successful in writing the CNATS on the first attempt.

Integrated curricula may be more suited to academically strong students (Whitley & Chadwick, 1986), and McMaster has been able to fill program places with highly qualified applicants (high school honours or A standing). Thus, finding a model that accounts for slightly more than 30% of the variance in performance in a very homogeneous group is considered significant (Norman & Streiner, 1994).

The findings of the present study support retaining both science and humanities courses as prerequisites to the program. High school English and chemistry grades emerged as predictive of success on the professional examination, consistent with a prior study (Horns, O'Sullivan, & Goodman, 1991). English courses may contribute to comprehension and writing skills, as well as "habits of analysis and reflection, introspection and self-examination" (Levine, 1995, p. 22). This conclusion is supported by the finding that nursing theory courses, in which personal writing and presentation skills are the outcome measure, were more predictive of success on the CNATS (a written examination) than were the clinical courses. Graduates of PBL curricula may perform better on "measures of humanism" (Vernon & Blake,

1993). During the tutorial process (PBL), a balance of science and humanism is brought to analysis of nursing situations, an outcome that the CNATS is designed to measure.

The analytic and problem-solving skills acquired in science classes may prepare students for critical problem-solving in nursing study and practice. The finding that science courses were a strong predictive variable of success on the CNATS, both as an admission variable (OAC chemistry) and as an in-program variable (human biological science and research methodology), supports the conclusion that these skills are used in writing these examinations. Although OAC biology was not considered a separate variable, because it is not a program requirement, the NEWADMAV for most of the study subjects contained additional science courses. Students who do well in both English and chemistry may have a particular facility for combining the scientific and humanistic aspects of nursing.

Early identification of students who will be unsuccessful academically is an important issue for nursing programs (Heupel, 1994). The basic sciences and the first-year nursing course were demonstrated to be early program predictors of success on the CNATS examinations. The greater contribution of theory courses (PBL in this curriculum), as compared with clinical grades, for predicting CNATS scores is consistent with other studies (Krupa, Quick, & Whitley, 1988). One study showed that science courses based on didactic principles relate well to nursing theory courses that require a high level of conceptual thought (Jacono et al., 1987). It is possible that the intellectual skills acquired in science and nursing theory courses are particularly useful in writing the CNATS examination.

The globally reported failure rates for the B.Sc.N. program for the years of the study ranged from 5% in 1992 to 10% in 1993, while the failure rate within the study sample ranged from 5% (2 of 36 subjects) in 1991 and 1992 (2/38) to 12.5% (5/40 subjects) in 1993. Although this is higher than the overall national standardized rate of 4%, the success rate was somewhat more stable over the years of the study than that reported in the results of a study by another Canadian university school (Jacono et al., 1987). Furthermore, the success rates of the entrants from high school closely resemble the success/failure rate among the "other qualifications" applicants; this finding differs from that of Froman and Owen (1989), who report a higher success rate among older students.

It is evident that most students admitted to the B.Sc.N. program using the present criteria successfully complete the educational program and are successful in their first attempt at writing the CNATS

examination. The 88% success rate of graduates on the examination may be attributable either to program variables or to stringent admission criteria. A move to criterion-referenced examinations may produce results different from those of the present study, and will thus require further research. One of the characteristics of a PBL-based curriculum is that students may not write regular formal examinations, as they do in traditional curricula; this may be a disadvantage for graduates, who then have to take a traditional multiple-choice examination. In 1991 the B.Sc.N. program introduced a voluntary practice examination to prepare the students for the experience of writing standardized examinations. This may have contributed to the stability of the failure rate during the years of the study. Further research will be conducted to determine the outcomes of these practice examinations and the relationship of success on these examinations and subsequent CNATS examinations.

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Le paradigme stress-coping, une contribution complémentaire des sciences sociales et des sciences infirmières au développement des connaissances

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This article provides an illustration of the combined contributions of social sciences and nursing in the development and application of knowledge. More specifically, the article presents a discussion of the respective contributions of the social sciences and nursing in the development of knowledge about the stress-coping paradigm. First, the significant role of the social sciences in initially developing the concepts of stress and coping is revealed through a review of different research perspectives considered to date, most notably in sociology and social psychology. After presenting some key markers in the development of nursing as a professional discipline, this paper illustrates how work developed through multidisciplinary efforts in the area of social sciences is pertinent to the development of theory, empirical research and the practice of nursing. The singular contribution of nursing to the development of knowledge in stress-coping is emphasized. The author concludes by noting that the discipline of nursing is somewhat similar to social sciences and shares some common interests, notably with regard to phenomena such as reaction to stress. The concepts of stress and coping are thus situated at the juncture of two bodies of knowledge.

La réflexion présentée dans cet article vise à fournir une illustration de la contribution mutuelle des sciences sociales et des sciences infirmières au développement et à l'application du savoir. Plus spécifiquement, une discussion sur les contributions respectives des sciences sociales et des sciences infirmières au développement des connaissances en regard du paradigme stress-coping est présentée. L'apport important des sciences sociales quant au développement original des concepts de stress et de coping est d'abord exposé en soulignant les différentes perspectives d'études considérées jusqu'à présent, notamment en sociologie et en psychologie sociale. Après avoir présenté quelques faits marquants liés au développement des sciences infirmières en tant que discipline professionnelle, l'exposé illustre ensuite en quoi les travaux développés à partir d'efforts multidisciplinaires dans le champ des sciences sociales sont pertinents au développement théorique, à la recherche empirique et à la pratique infirmière. La contribution singulière des sciences infirmières au développement du savoir dans ce domaine est mise en lumière. L'auteur conclut en notant que la discipline infirmière se rapproche du domaine des sciences sociales et en partage certains intérêts, notamment en regard de l'étude de phénomènes tel celui de la réaction au stress. Les concepts de stress et de coping se situent, dans cette perspective, à la jonction des savoirs.

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L'étude de la réaction au stress, intéressant depuis plusieurs décennies des chercheurs provenant de nombreuses disciplines, incluant les sciences infirmières, est issue d'observations répétées en regard de certaines différences individuelles qui existent quant à la façon de composer avec les événements importants de la vie. Suite à l'étude de Stouffer (1949) sur la fatigue de combat des soldats américains, depuis lors appelée stress post-traumatique, il est reconnu que certaines personnes n'ont pas les ressources suffisantes pour composer avec des traumatismes majeurs et conséquemment succombent rapidement à des désordres psychiatriques sous l'influence du stress. Ces constatations, provenant de l'histoire militaire américaine en regard de la vulnérabilité différentielle des individus, ont favorisé l'émergence d'un champ de recherche multidisciplinaire concernant l'étude des facteurs psychosociaux intervenant dans la réaction au stress (Aldwin, 1994). Plus particulièrement, depuis l'essor des conceptions multidimensionnelles de la santé, certains modèles multifactoriels expliquant la vulnérabilité des individus, des familles et des collectivités suite à des épisodes de stress ont été développés. C'est ainsi que le modèle linéaire et additif « stress-vulnérabilité-psychopathologie » a été graduellement remplacé par des modèles plus complexes et interactifs impliquant une constellation de facteurs, notamment des variables personnelles et contextuelles influençant la réaction au stress (Fry, 1989 ; Goodhart et Zautra, 1984 ; Lazarus et Folkman, 1984 ; McCubbin et Patterson, 1983 ; Pearlin, Mullan, Semple, et Skaff, 1990). D'après ces modèles, qui se situent dans un paradigme dit de « stress-coping » (Barnfather et Lyon, 1993), la perception du stress et les stratégies adaptatives ou de *coping* utilisées pour composer avec ces situations sont des facteurs-clés agissant comme médiateurs de la réaction au stress ou, en d'autres termes, comme facteurs de protection de la santé. Ces modèles sont le résultat de travaux tant théoriques qu'empiriques provenant de nombreuses disciplines intéressées aux déterminants de la santé, notamment la psychologie, la sociologie, la médecine psychiatrique et plus récemment les sciences infirmières, et se situent, dans cette perspective, à la jonction des savoirs.

L'objectif de ce manuscrit est de présenter différentes perspectives d'études des concepts de stress-coping, et d'illustrer en quoi ce paradigme, développé à partir d'efforts multidisciplinaires principalement dans le champ des sciences sociales, est pertinent au développement théorique, à la recherche et à la pratique en sciences infirmières. Les contributions respectives des sciences sociales et des sciences infirmières au savoir dans ce domaine seront plus particulièrement discutées.

**Le développement des concepts stress et coping,
une contribution importante des sciences sociales**

L'intérêt pour les concepts de stress et de *coping* a une très longue histoire dans le domaine des sciences sociales et de la psychologie. Il n'est pas erroné de mentionner que les études sur le concept d'aliénation, effectuées par les sociologues Marx, Weber et Durkheim, ainsi que les études dans le domaine de la psychopathologie et de la psychanalyse en regard des mécanismes intra-individuels de défense, notamment celles de Freud, ont précédé les travaux que nous connaissons aujourd'hui.

Par ailleurs, depuis l'émergence des études portant spécifiquement sur la réaction au stress, trois conceptualisations majeures de la notion de stress, issues de disciplines différentes, ont été proposées dans les écrits. Il s'agit du stress considéré comme une réponse de l'organisme, du stress considéré comme un stimulus de l'environnement interne ou externe de la personne et, enfin, du stress considéré comme une transaction entre la personne et son environnement. Selye (1956), un physiologiste, est l'un des premiers chercheurs à avoir proposé une théorie du stress, appelée Syndrome général d'adaptation (SGA), congruente avec une définition du stress en tant que réponse de l'organisme. Selon cette théorie, qualifiée de générale, la réaction individuelle au stress n'est pas spécifique au type de stressor ou au contexte qui l'entoure, mais se manifeste de la même manière, quels que soient le stress et la situation. Il s'agit d'une réponse physiologique hormonale défensive de l'organisme à toute forme d'agression physique, psychologique ou sociale, en vue de rétablir l'homéostasie interne.

Plus récemment, les travaux de quelques épidémiologistes ont permis de définir le stress comme un stimulus de l'environnement auquel la personne est exposée. Ces auteurs soutiennent, tout comme Selye, des modèles généraux selon lesquels les expériences stressantes de la vie augmentent la vulnérabilité d'une personne à la maladie (Antonovsky, 1979; Cassel, 1976). Dans cette perspective, on ne peut passer sous silence les travaux classiques de Holmes et Rahe (1967) et de Holmes et Masuda (1974) sur les événements de la vie et leur relation avec la santé mentale.

Ces modèles généraux ont toutefois démontré quelques faiblesses quant à leur pouvoir prédictif en regard de la santé. Ils soulignent le rôle du stress sur la vulnérabilité à la maladie mais ne font aucune référence à des paramètres d'ordre psychosociaux qui pourraient être impliqués dans la réaction au stress, de même qu'au contexte spécifique

de cette réaction. En contrepartie à ces modèles généraux d'explication, des cadres théoriques issus de la médecine psychosomatique (telle la psychoneuroimmunologie) et des sciences sociales ont permis plus récemment de mettre en évidence les réactions spécifiques au stress, notamment le contexte dans lequel la réaction au stress se produit, ainsi que l'influence de facteurs médiateurs. En sciences sociales plus particulièrement, le paradigme *stress-coping* est basé sur le postulat que le stress est associé à un large éventail de problèmes de santé et que les stratégies adaptatives personnelles et familiales (stratégies de *coping*) sont des ressources médiatrices importantes qui réduisent l'impact du stress sur la santé (Billings et Moos, 1982 ; Lazarus, 1981). Ces modèles, plus récents, s'inspirent de la troisième définition du stress selon laquelle le stress est considéré comme une transaction entre la personne et son environnement. Ces modèles se distinguent par le fait qu'ils accordent une place prépondérante au concept de *coping*.

Dans cette perspective, le modèle théorique du stress et du *coping* de Lazarus (Lazarus, 1966 ; Lazarus et Folkman, 1984), en psychologie sociale, est probablement le plus connu actuellement et le plus utilisé comme cadre théorique dans les recherches empiriques. Selon ce modèle, le stress est considéré comme une transaction qui excède les ressources de la personne et qui nécessite des efforts d'adaptation. Lazarus décrit plus particulièrement un processus dynamique selon lequel la personne apprécie le stress auquel elle est confrontée (notamment sa signification et son importance), ainsi que les ressources dont elle dispose pour y faire face, et fournit des efforts pour composer avec ce stress. Le *coping* est, dans cette perspective, l'ensemble des efforts cognitifs et comportementaux qu'une personne exerce afin de maîtriser la situation ou réduire les demandes associées à cette situation, qu'il s'agisse d'un événement de vie particulier ou d'un stress chronique de la vie quotidienne. Les stratégies de *coping* ont une fonction instrumentale et sont, dans ce cas, centrées sur la réduction ou l'élimination du problème qui est source de stress. Elles ont également une fonction palliative visant à régulariser les émotions associées à la situation problématique. Selon Lazarus, les résultats à long terme d'un processus de *coping* efficace, c'est-à-dire d'un processus où les stratégies utilisées sont ajustées à la nature de la situation de stress, sont : un meilleur fonctionnement social, ainsi qu'une bonne santé et qualité de vie.

Contrairement à une vision unidirectionnelle, statique ou encore à un modèle linéaire antécédent-conséquence, ce modèle transactionnel considère la personne et l'environnement en relation dynamique, mutuellement réciproque et bidirectionnelle. De nombreuses études empiriques, effectuées à partir de ce cadre théorique, en soutiennent les

propositions. En fait, l'influence de l'appréciation des stressseurs et des stratégies adaptatives sur différentes facettes de la qualité de vie a été démontrée à maintes reprises dans plusieurs domaines d'investigation (pour des revues d'écrits, voir Aldwin, 1994 et Barnfather et Lyon, 1993).

Le cadre théorique de Lazarus se situe dans une perspective de psychologie cognitive individuelle. L'intérêt pour les concepts de stress et de *coping* est par ailleurs également présent depuis longtemps dans les domaines de la sociologie et de l'anthropologie. Ces disciplines soulignent le rôle majeur de la société et de la culture en regard du développement de la détresse psychologique et de la maladie mentale, ainsi que des formes d'expression de ces affections. Dans cette perspective, l'origine des troubles associés au stress ne résiderait pas tant à l'intérieur de l'individu mais plutôt au sein de l'environnement socio-culturel.

En sociologie, ce sont principalement les théoriciens et chercheurs contemporains intéressés à la famille en tant que système social qui se sont plus particulièrement penchés sur l'étude des concepts de stress et de *coping*. C'est ainsi que le modèle théorique de Hill (1949), premier modèle expliquant le phénomène de la crise familiale en réaction à des événements de vie marquants tels la séparation prolongée des membres de la famille, le modèle de l'ajustement et de l'adaptation familiale au stress de McCubbin et Patterson (1983) et ses variantes, ainsi que le modèle d'intervention préventive de Boss (1988) ont servi de cadre de référence à la plupart des recherches effectuées dans le domaine du stress familial. Depuis les années soixante-dix, un nombre croissant d'études ont ainsi été entreprises afin d'identifier les stratégies adaptatives que les familles utilisent afin de composer avec différentes situations de stress (Coelho, Hamburg et Adams, 1974; McCubbin, 1979; McKenry et Price, 1994; Moos, 1976).

Il importe de souligner que les développements théoriques et empiriques, effectués à partir de cette perspective sociologique des concepts de stress et de *coping*, ont permis d'élargir la portée des travaux réalisés dans ce domaine à un niveau davantage macroscopique et systémique. Une hypothèse à la base de cette perspective de recherche est que l'utilisation de stratégies de *coping* efficaces renforcent ou maintiennent les ressources familiales, notamment la cohésion et l'adaptabilité, ce qui protège la famille des conséquences néfastes du stress (Burr, 1973; Hill, 1949). Un *coping* familial efficace concerne plus spécifiquement la gestion de plusieurs dimensions de la vie familiale telles la promotion de l'autonomie et de l'estime de soi des membres de la

famille, le développement d'un réseau de soutien social lors des transactions avec l'environnement communautaire et l'acquisition d'un sens de contrôle en regard des stressseurs et des changements dans l'unité familiale.

La recherche dans ce domaine familial s'est inspirée largement de la théorie de Lazarus (1966) en psychologie sociale, théorie dont nous avons discuté précédemment, ainsi que de certaines théories sociologiques, notamment celle de Pearlin et Schooler (1978). Ces deux auteurs ont plus spécifiquement proposé une approche où le *coping* réfère aux comportements qui protègent les personnes contre les dommages psychologiques associés aux expériences sociales problématiques. Dans cette optique, la fonction protectrice des comportements de *coping* peut s'exercer selon trois modalités, soit : en éliminant ou en modifiant les conditions qui suscitent les problèmes ; en contrôlant perceptuellement la signification de l'expérience de telle sorte que le caractère problématique de la situation est neutralisé ; et en conservant les conséquences émotionnelles des problèmes dans des limites manoeuvrables.

Ainsi, même si certaines similitudes existent quant aux diverses façons de conceptualiser la notion de *coping*, il n'en demeure pas moins qu'il s'agit d'une notion complexe en raison des centres d'intérêts variés des disciplines qui s'y intéressent. Dans cette perspective, Pearlin et Aneshensel (1986) ont apporté une contribution intéressante en tentant de préciser les trois approches les plus fréquemment utilisées par les chercheurs et les théoriciens afin d'expliquer les différentes fonctions du *coping* sur la santé. La première approche, qu'ils ont appelée le « paradigme du stress », souligne que le *coping* peut agir comme barrière aux conséquences néfastes du stress sur la santé. Dans la deuxième approche, orientée vers les comportements de santé (« paradigme des comportements de santé »), le *coping* est considéré comme un mécanisme permettant de modifier les comportements à risque pour la santé ; par exemple, les stratégies de gestion du stress peuvent diminuer les comportements tels la consommation d'alcool ou de drogues. Enfin, la troisième approche, nommée « paradigme des comportements liés à la maladie », souligne le rôle du *coping* dans le soulagement et la réduction des problèmes d'ajustement liés à la maladie.

Pearlin (1989) est l'un des rares auteurs à avoir accordé une importance prépondérante au contexte de la réaction au stress, notamment en considérant les valeurs individuelles et collectives, les ressources personnelles (incluant les ressources socio-économiques) et l'importance de la culture en tant que facteurs potentiellement influents sur la réac-

tion au stress. Cet auteur postule que la réaction au stress ne s'effectue pas sous vide; conséquemment, l'étude de cette réaction et l'intervention qui en découle doivent tenir compte des facteurs contextuels.

Le concept de *coping* a aussi été considéré sous l'angle des ressources de *coping*, ou à partir de ce qu'Antonovsky (1979) a appelé les ressources de résistance généralisées. Il s'agit plus particulièrement des ressources personnelles qui affectent l'étendue des stratégies qui sont considérées et les efforts qui sont entrepris afin de composer avec le stress (Moos et Billings, 1982). Selon cette approche, certaines attitudes et habiletés augmentent le potentiel des individus à composer de façon efficace avec le stress. Les recherches actuelles, tenant compte de cette conceptualisation, soulignent plus particulièrement l'influence de certaines caractéristiques personnelles, notamment le sens de la maîtrise des événements (Wheaton, 1983, 1985), le sens de l'auto-efficacité (Bandura, 1977) et la hardiesse (Kobasa, Maddi et Khan, 1984) en tant que facteurs ayant une influence sur la relation existant entre le stress et la santé.

Dans cette même perspective, un autre champ de connaissance spécifique s'est développé, soit celui des traits ou des styles de *coping* permettant de faire face au stress. Contrairement à l'approche transactionnelle de Lazarus où il est proposé que les stratégies adaptatives utilisées se modifient ou varient selon les situations stressantes et le contexte, la notion de trait ou de style de *coping* fait appel à des caractéristiques stables de la personnalité de l'individu et à la notion de mécanismes de défense qui peuvent, dans certaines circonstances, être des mécanismes sains d'adaptation au stress (Vaillant, 1977). Les recherches effectuées dans ce domaine tentent d'identifier certaines caractéristiques liées à la personnalité qui expliquent les différences chez les individus, en ce qui a trait à la réaction au stress. Cette approche prend pour acquis qu'une personne compose avec toutes les situations stressantes, qu'il s'agisse de stress aigu, de stress chronique ou encore de stress de la vie quotidienne, selon son style de *coping* et ce, indépendamment des conditions environnementales (Endler et Parker, 1990).

En résumé, on peut constater que les concepts de stress et de *coping* ont été étudiés sous différents angles. Il ont d'abord intéressé des chercheurs du monde bio-médical mais de récents efforts de conceptualisation peuvent être attribués aux disciplines des sciences sociales. Ces disciplines ont chacune, selon leur propre cadre de référence, précisé certaines dimensions de ces concepts et ont ainsi contribué au développement du savoir théorique et empirique dans ce domaine.

Mais qu'en est-il des concepts stress et coping en sciences infirmières ?

Afin de délimiter la contribution des sciences infirmières à ce vaste champ d'étude multidisciplinaire et considérant, à l'instar de Carper (1978), que le caractère spécifique de toute discipline détermine le type de connaissances à développer, ainsi que les approches utilisées pour le développement du savoir, il nous apparaît important de préciser brièvement la nature des sciences infirmières en tant que discipline professionnelle, de même que son intérêt pour les concepts stress et *coping*.

Ainsi, dès l'époque de Nightingale, on relève dans les écrits une préoccupation pour le concept d'adaptation au stress lié à la condition de santé ; le succès des réponses adaptatives d'une personne à la maladie dépend des forces environnementales (Nightingale 1858/1959). Par ailleurs, ce n'est qu'au début des années cinquante, ce qui est relativement récent, que des infirmières se sont à nouveau intéressées à délimiter le champ de leur discipline. C'est alors qu'un nouveau débat commence à surgir : l'élaboration de théories « uniques », par opposition à l'emprunt de théories à des disciplines connexes, notamment aux sciences bio-médicales et aux sciences sociales, afin de décrire, expliquer et prédire certains phénomènes d'intérêt en sciences infirmières.

Suivant les travaux de Kuhn (1970) sur la structure de la révolution scientifique et le phénomène du paradigme dominant, la discipline infirmière reconnaît actuellement une orientation cognitive à son développement, plus spécifiquement quatre métaconcepts qui servent de charpente pour délimiter son champ d'investigation : il s'agit de la *santé*, de la *personne* (incluant la famille et la communauté), de l'*environnement* et du *soin*, appelés concepts du métaparadigme infirmier (Fawcett, 1984). C'est ainsi que les discussions contemporaines s'articulent autour de ces quatre concepts centraux et que les théories élaborées ou empruntées aux disciplines connexes tentent d'explorer, de décrire, d'expliquer et de prédire des phénomènes qui touchent ces concepts et leur interrelation, notamment les phénomènes du stress et du *coping*.

Ainsi, l'étude des patterns de comportements humains de santé en relation avec l'environnement a été identifiée comme étant un thème majeur pour le développement des connaissances en sciences infirmières (Donaldson et Crowley, 1978). Plus récemment, l'énoncé suivant a été proposé comme étant le centre d'intérêt de la discipline infirmière : « La discipline infirmière s'intéresse au soin de la personne qui, en interaction continue avec son environnement, vit des expériences de

santé» (Kérouac, Pepin, Ducharme, Duquette et Major, 1994, p. 60). Les expériences de santé concernent des situations relatives à la croissance, au développement et à diverses problématiques, incluant la maladie. Les concepts de stress et de *coping* sont implicites au sein de ce centre d'intérêt selon lequel le rôle de l'infirmière consiste à aider les personnes, familles et communautés, à composer avec leurs différentes expériences de santé.

*La pertinence des concepts stress et coping
pour la théorie et la recherche en sciences infirmières*

Certaines théoriciennes en sciences infirmières ont proposé des modèles conceptuels précisant la contribution sociale de la discipline infirmière à la santé et au sein desquels les concepts de stress et de *coping* se retrouvent comme éléments charnières (Gottlieb et Rowat, 1987 ; Roy et Andrews, 1991). Le modèle de Callista Roy (Roy et Andrews, 1991) offre une illustration particulièrement intéressante de l'utilisation du paradigme stress-coping en sciences infirmières. Cette auteure a puisé dans la théorie des niveaux d'adaptation de Helson (1964), la théorie générale des systèmes de von Bertalanffy (1968) et les théories dans le domaine de la psychologie sociale concernant le stress (Coelho, Hamburg et Adams, 1974 ; Lazarus et Folkman, 1984), pour élaborer son modèle conceptuel. Ce modèle précise un but explicite aux soins infirmiers, soit celui de viser la promotion du processus dynamique qu'est l'adaptation des individus et des groupes (familles, communautés) à leur environnement. L'objet de l'intervention infirmière est d'agir sur les stimuli ou facteurs de l'environnement (stresseurs) dans le but d'obtenir des réponses adaptées maintenant à l'intégrité bio-psycho-sociale des personnes et des groupes, en vue de favoriser leur qualité de vie. La personne est, dans cette perspective, considérée comme un système d'adaptation qui utilise des processus internes afin d'atteindre ses objectifs individuels de survie, de croissance, de reproduction et de développement. Ces processus concernent deux catégories de mécanismes de *coping*, façons innées ou acquises de répondre aux stresseurs ou stimuli de l'environnement : les mécanismes régulateurs qui fonctionnent par l'intermédiaire de processus physiologiques et les mécanismes cognitifs qui sont délibérés.

Une théoricienne canadienne, Moyra Allen, a également élaboré un modèle pour la discipline infirmière orienté vers la promotion de la santé familiale et tenant compte du concept de *coping* familial. Selon ce modèle (voir Kravitz et Frey, 1989), la santé est un processus social comprenant des attributs interpersonnels et des processus d'apprentis-

sage, notamment le *coping* familial. La philosophie des soins de santé primaire (Organisation mondiale de la santé, 1978) et la théorie de l'apprentissage social de Bandura (1977) sont à la base de ce modèle. Selon cette conception, le but premier des soins infirmiers est la promotion de la santé familiale, soit le maintien, le renforcement et le développement de la santé de la famille et de ses membres par l'activation de leur processus d'apprentissage incluant l'apprentissage de stratégies adaptatives efficaces face aux situations de santé. Les stratégies adaptatives ou de *coping* sont considérées comme étant modifiables par une intervention de collaboration infirmière-famille (Kérouac, Pepin, Ducharme, Duquette et Major, 1994). Ces stratégies correspondent plus précisément aux efforts faits en vue de composer avec des situations problématiques et leur but est la maîtrise ou la résolution des problèmes. Le *coping* est fonction du processus utilisé pour résoudre les difficultés et inclut différentes activités telles que l'identification de la situation problématique, l'identification de solutions alternatives et l'évaluation de ces solutions. Les effets attendus de cette série d'activités sont l'amélioration de l'état de santé et du fonctionnement familial, la satisfaction en regard de la résolution du problème et une amélioration de la qualité de vie.

Le modèle de King (1981) offre une autre illustration de la pertinence des concepts stress et *coping* pour la discipline infirmière. Cette théoricienne conceptualise la personne comme un système ouvert en interaction avec son environnement et la santé comme une adaptation aux stressseurs de l'environnement interne et externe. Le soin infirmier consiste en une transaction avec la personne visant la réduction de la tension ou du stress et considérant l'atteinte des buts personnels. Une importance particulière est accordée au processus de *coping* permettant une compréhension des réponses de l'individu qui doit faire face à des problèmes de santé.

En somme, plusieurs modèles de la discipline infirmière où les concepts de stress et de *coping* sont centraux ont été élaborés au cours des vingt dernières années. Ces modèles sont des matrices disciplinaires considérées comme des cadres de références généraux guidant la théorie, la pratique et la recherche. Les propositions énoncées dans ces modèles sont générales et n'ont pas été élaborées dans le but d'être vérifiées empiriquement au même titre que des théories (Fawcett, 1991). C'est dans cette perspective que la discipline infirmière a eu recours, pour le développement des connaissances, à certaines théories empruntées de disciplines connexes qui ont de plus longues traditions de recherche, notamment les sciences sociales et la psychologie.

De nombreux travaux en sciences infirmières basées sur le modèle conceptuel de Roy ont ainsi eu recours au cadre théorique de Lazarus afin d'opérationnaliser et de mesurer, à l'aide d'indicateurs empiriques, le concept de *coping* (Calvillo et Flaskerud, 1993 ; Frederickson, Jackson, Strauman et Strauman, 1991 ; Pepin et al., 1994). D'autres recherches, basées sur la conception des sciences infirmières d'Allen, ont eu recours à la théorie sociologique de l'adaptation familiale de McCubbin et Patterson (1983) pour définir le concept de *coping* familial (Ducharme et Rowat, 1992). Les théories développées dans d'autres disciplines ont néanmoins été utilisées en sélectionnant des propositions et des concepts pertinents à la discipline infirmière et en traduisant leur utilité dans une perspective infirmière (Crawford, Dufault et Rudy, 1979).

En ce qui a trait au contenu des études empiriques en sciences infirmières, de nombreuses recherches réalisées au cours des dernières années ont permis de décrire la nature et l'efficacité de différentes stratégies adaptatives face à des stressseurs aigus et chroniques associés à l'expérience de santé des individus, des familles et des collectivités (pour une revue des écrits voir Barnfather et Lyon, 1993). Les connaissances générées de ces recherches permettent aujourd'hui d'élaborer des interventions afin de promouvoir l'utilisation de telles stratégies réduisant l'effet du stress et favorisant le bien-être et la qualité de vie.

Il importe par ailleurs de souligner qu'en sciences infirmières, les concepts de stress et de *coping* ont été graduellement étudiés sous de nouveaux angles. Comme dans toutes les disciplines, de grands courants de pensée ont influencé le développement des connaissances théoriques et empiriques en sciences infirmières, et particulièrement les connaissances concernant ces concepts. Le premier de ces courants, nommé « courant de la catégorisation » et caractérisé par une philosophie positiviste et la recherche de lois universelles (Kérouac, Pepin, Ducharme, Duquette et Major, 1994) a marqué fortement, à ses débuts, le développement de la connaissance. Même si cette influence est toujours présente, plusieurs théoriciennes et chercheuses se questionnent actuellement sur la pertinence de cette approche considérée insuffisante pour explorer la philosophie humaniste du soin infirmier (Phillips, 1992). C'est ainsi qu'un nouveau courant de pensée, celui de la « transformation », selon lequel la personne est considérée comme un tout unitaire en constante interaction avec un environnement changeant, a graduellement vu le jour (Kérouac, Pepin, Ducharme, Duquette et Major, 1994). Cette vision nouvelle s'accompagne d'une utilisation de plus en plus fréquente de méthodes de recherche dites « naturalistes » issues des sciences sociales, approches congruentes avec une vision philosophique et épistémologique des sciences infirmières. Ces nou-

velles méthodes, utilisées de plus en plus dans les études concernant l'adaptation au stress (Bargagliotti et Trygstad, 1987 ; Saunders et McCorkle, 1987), laissent entrevoir des pistes intéressantes de découverte, plus spécifiquement une ouverture au développement de théories par voie inductive à partir d'observations ancrées dans la réalité pratique. Elles ont tout le potentiel de contribuer au développement du savoir dans le domaine du stress et du *coping*.

Par ailleurs, certaines approches théoriques, telle celle de la théorie critique, ont aussi été proposées récemment afin de favoriser un développement autonome des sciences infirmières en regard de l'étude des phénomènes de santé (Allen, Benner et Diekelmann, 1986 ; Stevens, 1989). L'approche critique est une perspective de recherche réflexive dont l'objectif est la production de connaissances qui permettent à des personnes de se libérer de leurs contraintes conscientes et inconscientes (Campbell et Bunting, 1991). L'approche féministe, basée sur des dynamiques et des processus similaires en regard de la critique de la domination, est également de plus en plus utilisée afin de favoriser le développement autonome des sciences infirmières (Bunting et Campbell, 1990). Ces deux approches sont des approches analytiques et méthodologiques des phénomènes pertinents à la discipline infirmière, notamment la santé et ses divers constituants, dont les phénomènes de stress et de *coping*. Il s'agit d'approches selon lesquelles théorie et pratique sont intimement imbriquées (Thompson, 1987). L'intérêt nouveau dans la discipline infirmière pour les méthodes de recherche naturalistes et les théories critiques est une illustration de la complémentarité entre les sciences sociales, où les racines de ces approches et théories ont pris naissance, et les sciences infirmières qui en font une application en fonction de leur champ d'intérêt en regard de la santé.

La pertinence des concepts stress et coping pour la pratique infirmière

L'attrait de la discipline infirmière pour les concepts stress et *coping* est étroitement relié à la pertinence de ces concepts sur le plan de la pratique. Tel que mentionné précédemment, les infirmières offrent une pratique centrée sur le soin, au sein d'environnements variés, à des individus, à des familles et à des communautés qui font face à de multiples expériences liées à leur santé ; plus spécifiquement, elles travaillent quotidiennement auprès de personnes qui vivent des transitions normales de la vie telles la naissance et la mort, des événements majeurs de la vie tels la maladie aiguë, l'hospitalisation, le décès d'un proche, ou encore des stressseurs de la vie quotidienne associés au vieillissement et à la maladie chronique. C'est la façon dont les individus,

les familles et les collectivités composent et apprennent à composer avec ces situations de stress qui retiennent particulièrement l'attention des infirmières.

C'est plus spécifiquement la notion de processus de *coping*, dont la définition implique un changement selon les situations de stress et le contexte, qui est pertinente pour la pratique infirmière, plutôt que la notion de traits ou styles de *coping* qui reflète des caractéristiques relativement stables de la personnalité. En fait, considérer le *coping* en tant que processus souligne le caractère « modifiable » ou malléable des stratégies adaptatives et permet d'envisager l'apprentissage de ces stratégies et, conséquemment, des interventions éducatives auprès de la clientèle des soins infirmiers.

C'est dans cette optique que plusieurs types de programmes d'intervention ont été développés par les praticiennes et les chercheuses en sciences infirmières et ce, à partir des diverses définitions du stress (pour des revues d'écrits, voir Egan, 1993, et Snyder, 1993). La plupart de ces programmes s'appuient sur les trois principales définitions qui ont été présentées dans les pages précédentes, soit : le stress considéré comme une réponse de l'organisme, le stress considéré comme un stimulus de l'environnement interne ou externe de la personne et, enfin, le stress considéré comme une transaction entre la personne et son environnement.

Les programmes d'intervention infirmière où le stress est considéré comme une réponse de l'organisme à une agression sont articulés autour des travaux de Selye (1956) sur le syndrome général d'adaptation et sont les premiers à avoir été élaborés. Ces interventions sont centrées sur diverses manifestations du stress telles l'anxiété, l'irritabilité, la détresse ou encore la maladie, et visent la gestion du stress par l'apprentissage de méthodes telles la relaxation musculaire, la méditation, le biofeedback et l'exercice afin de contrôler la réactivité des personnes aux agents de stress. Plusieurs infirmières ont élaboré et évalué de tels programmes auprès de clientèles variées confrontées à des stress divers liés à l'état de santé (Bowers, 1983 ; Lerman et al., 1990 ; Moore et Altmaier, 1981 ; Pender, 1985).

Les programmes où le stress est considéré comme un stimulus sont, quant à eux, basés sur le postulat que la personne peut contrôler les conditions environnementales qui agissent comme sources de stress. Ces programmes visent à redonner aux individus le sens de maîtrise ou d'auto-efficacité face aux situations de stress qu'ils rencontrent et sont basés principalement sur les travaux sociologiques concernant les ressources de *coping* personnelles face aux agressions de l'environ-

nement. Plusieurs de ces programmes, élaborés par des infirmières, concernent l'effet de l'information et de l'enseignement sur la réduction du stress lié à une condition de santé spécifique (Johnson, Christman et Stitt, 1985; Rice, Sieggreen, Mullin et Williams, 1988; Ziemer, 1983). Les travaux de Jean Johnson concernant l'effet de l'information sur les patients qui doivent subir une chirurgie sont, dans cette perspective, parmi les plus connus (Johnson, Christman et Stitt, 1985; Johnson, Fuller, Endress et Rice, 1978; Johnson, Kirchoff et Endress, 1975; Johnson, Morrissey et Leventhal, 1973; Johnson, Rice, Fuller, et Endress, 1978).

Enfin, les programmes d'intervention basés sur une définition transactionnelle du stress, issue de la psychologie sociale, prennent en considération autant les caractéristiques de la personne que celles de la situation et de son contexte. Ces programmes accordent une importance aux processus subjectifs d'appréciation cognitive des situations de stress en vue d'une amélioration de la relation entre la personne et son environnement. Ils visent plus particulièrement à favoriser une appréciation réaliste des situations de stress, en considérant les options et les ressources disponibles dans le contexte de vie et un entraînement à l'utilisation de stratégies adaptatives efficaces et ajustées à la nature des transactions personne-environnement (Mohide et al., 1990; Roberts et al., 1995). Ces programmes émergent de la perspective transactionnelle de Lazarus et se situent actuellement au coeur du courant de pensée de la transformation qui accorde, au sein de la discipline infirmière, une place privilégiée aux multiples réalités des personnes, aux significations des expériences humaines de santé et à l'interaction réciproque entre la personne et son environnement.

Afin d'illustrer les propos qui ont été énoncés dans les pages précédentes, il apparaît pertinent de fournir un exemple concret de l'articulation étroite existant entre les connaissances issues des sciences sociales et celles qui émergent de la recherche, de la théorie et de la pratique en sciences infirmières en regard du paradigme *stress-coping*. Pour ce faire, une étude empirique en sciences infirmières dans laquelle le cadre de référence retenu combinait à la fois un modèle conceptuel en sciences infirmières, plus particulièrement le modèle d'Allen (Kravitz et Frey, 1989) et un modèle théorique en sociologie, soit celui de l'adaptation familiale de McCubbin et Patterson (1983), est décrite dans la section suivante (Ducharme et Rowat, 1992; Ducharme, 1994). Les implications de cette étude pour le développement du savoir et la pratique infirmière sont dégagées.

**Une illustration de la contribution complémentaire
des sciences sociales et des sciences infirmières
au développement des connaissances**

Cette illustration provient d'une étude longitudinale qui a été réalisée à partir du modèle d'Allen selon lequel un des rôles de l'infirmière consiste à favoriser, auprès des familles, l'apprentissage de stratégies adaptatives efficaces face aux différentes situations de santé qu'elles rencontrent. Cette étude est issue de certaines observations cliniques et constatations empiriques à l'effet que : 1) les stressseurs quotidiens, notamment les stressseurs associés aux problèmes de santé chronique, occupent une place prépondérante dans la vie des personnes âgées et que 2) les recherches sur les facteurs psychosociaux associées à la qualité de vie des couples âgés confrontés à de tels stressseurs sont pratiquement inexistantes.

Afin de spécifier les variables à l'étude et de les opérationnaliser dans un processus systématique de recherche, le modèle théorique des sociologues McCubbin et Patterson, selon lequel le soutien et les stratégies adaptatives familiales sont des variables-clés favorisant l'adaptation au stress, a été considéré. Le choix de ce cadre théorique a permis, dans la perspective de cette étude, de préciser la perspective générale disciplinaire du modèle conceptuel d'Allen.

Cette étude visait plus précisément à vérifier certaines propositions du modèle de McCubbin, propositions pertinentes pour la discipline infirmière tenant compte du lien entre la *personne (famille)*, la *santé*, l'*environnement* et le *soin* ou l'intervention infirmière. Elle visait à tester ces propositions auprès d'une population spécifique rencontrée dans la pratique infirmière, en l'occurrence une population de conjoints âgés confrontés à des stressseurs chroniques quotidiens associés à leur situation de santé. Un des buts de cette recherche était notamment de vérifier la relation existant entre certaines caractéristiques du soutien conjugal, la nature des stratégies adaptatives ou de *coping* utilisées afin de composer avec les stressseurs quotidiens, et des indicateurs de qualité de vie, entre autres, la perception de l'état de santé, la satisfaction de vie générale et la satisfaction en regard de la vie conjugale.

Au premier temps de cette étude, des entrevues à domicile ont été réalisées auprès de 135 couples âgés de plus de soixante-cinq ans (270 conjoints) à l'aide d'instruments de mesure élaborés, entre autres, par McCubbin et ses collègues (McCubbin, Olson et Larsen, 1987) et conséquemment congruents avec la perspective théorique de l'étude.

De ces conjoints, 180 sujets ont de nouveau été interviewés deux ans plus tard afin de vérifier la stabilité des résultats avec le temps. Les analyses effectuées ont démontré, pour les deux moments de la collecte des données, une relation positive entre la perception d'une disponibilité et d'une réciprocité du soutien conjugal et les indicateurs de qualité de vie. Par ailleurs, parmi plusieurs stratégies de *coping* considérées dans cette étude et proposées par le cadre théorique de McCubbin, soit la recherche de soutien spirituel, la recherche d'aide provenant des services sociaux et de santé, la recherche de soutien auprès du réseau social, le processus de résolution des problèmes et le recadrage des situations problématiques, la contribution significative d'une seule stratégie adaptative à la qualité de vie des conjoints a été démontrée. Cette stratégie de *coping*, « le recadrage des situations problématiques », consiste à reformuler les situations problématiques en termes plus malléables. Il s'agit d'une stratégie cognitive qui se rapproche du concept d'appréciation cognitive proposé par Lazarus et Folkman (1984). Il importe de noter qu'aucune des stratégies adaptatives faisant appel à une recherche de soutien à l'extérieur de la dyade conjugale ne fut associée, dans cette étude, à l'un ou l'autre des indicateurs de qualité de vie.

Les analyses effectuées dans le cadre de cette étude ont également permis de proposer un modèle de relation entre les variables considérées. Selon ce modèle, le soutien conjugal a non seulement un effet direct, mais également un effet indirect sur la qualité de vie. Les résultats suggèrent plus précisément que la perception d'une disponibilité et d'une réciprocité du soutien conjugal favorise l'utilisation de la stratégie de recadrage, stratégie qui favorise en retour la qualité de vie des conjoints âgés.

Ces résultats, en dépit du fait qu'ils soient présentés ici fort sommairement, offrent des pistes précises pour l'intervention infirmière auprès de cette population vieillissante, pistes tenant compte des perspectives disciplinaires proposées par le modèle conceptuel d'Allen. C'est ainsi que suite à cette étude, un projet d'intervention sera implanté sous peu afin de favoriser, auprès de la population âgée, non pas l'utilisation de ressources sociales à l'extérieur de la dyade conjugale mais plutôt l'apprentissage et l'utilisation de stratégies de *coping* d'ordre cognitif ainsi que de stratégies concrètes visant à faciliter l'échange d'aide instrumentale et affective entre conjoints âgés (réciprocité). Ces modalités d'interventions sont conformes aux visées d'Allen concernant la mission sociale de l'infirmière, c'est-à-dire celle de favoriser l'apprentissage de stratégies adaptatives efficaces auprès des familles et découlent de connaissances empruntées à la sociologie.

Cette étude a permis de vérifier certaines propositions théoriques du modèle de McCubbin et Patterson (1983) auprès d'une population particulière de personnes âgées confrontées à des stressseurs quotidiens associés à leur expérience de santé. Dans cette perspective, cette recherche en sciences infirmières contribue au développement du savoir en sciences sociales. Elle est une illustration concrète des contributions mutuelles de ces disciplines connexes.

Des concepts à la jonction des savoirs...

La réflexion présentée dans cet article se veut une illustration de la contribution mutuelle des sciences sociales et des sciences infirmières au développement et à l'application du savoir. Le domaine d'étude du stress et du *coping*, choisi pour ce faire, est un domaine riche et stimulant qui permet l'intégration d'approches scientifiques provenant d'une variété de disciplines. Ainsi, les travaux multidisciplinaires effectués en regard de ces concepts contribuent à ce que certains auteurs américains qualifient de *shared knowledge* (Stevens, 1984).

En tant que discipline professionnelle, les sciences infirmières contribuent non seulement à l'application directe de connaissances acquises au sein de disciplines académiques ou fondamentales, mais également au développement de théories permettant de guider l'action et le changement. Tel que souligné précédemment, l'attrait de la discipline infirmière pour les concepts de stress et de *coping* est de longue date et est étroitement relié à la pertinence de ces concepts sur le plan de la pratique. Les infirmières offrent des soins au sein d'environnements variés à des individus, à des familles et à des communautés qui font face à de multiples expériences liées à leur santé, expériences qui peuvent être appréciées comme étant des situations de stress aigu, chronique ou encore des stressseurs de la vie quotidienne. C'est la façon dont ces individus, familles et collectivités composent ou peuvent apprendre à composer avec ces situations de stress qui retient particulièrement l'attention des infirmières. Sachant que des stratégies de *coping* efficaces sont associées positivement à la santé et à la qualité de vie, le paradigme stress-coping prend toute son importance et est des plus pertinents pour la discipline infirmière.

Par ailleurs, même s'il faut admettre que le développement des connaissances en sciences infirmières en regard de ces concepts n'en est actuellement qu'à ses débuts, les travaux effectués jusqu'à présent ont permis non seulement d'identifier ces concepts comme offrant un intérêt pour la discipline infirmière, mais également de les associer à

des phénomènes de santé et, tel que nous l'avons mentionné, d'élaborer certaines interventions favorisant la santé et la qualité de vie des clientèles des soins infirmiers. Ces efforts ont principalement contribué au développement de théories « descriptives », développement effectué principalement à partir des travaux réalisés au sein de disciplines ayant de plus longues traditions de recherche, notamment les sciences biomédicales et les sciences sociales. Le développement de théories dites « prescriptives » est toutefois proposé comme étant une voie privilégiée permettant aux sciences infirmières de contribuer de façon singulière à l'avancement des connaissances dans ce vaste champ d'investigation (Dickoff, James, et Wiedenbach, 1968). De telles théories fournissent des pistes pour l'intervention ou l'application du savoir.

Dans cette optique, les approches inductives étant de plus en plus reconnues et valorisées en sciences infirmières, du fait qu'elles permettent un développement théorique et empirique ancré dans la réalité des observations provenant du « terrain », de nouvelles connaissances devraient émerger au cours des prochaines années. En fait, le changement graduel de courant de pensée au sein de la discipline infirmière, qu'il s'agisse de la philosophie du soin qui est définie comme humaniste par un nombre croissant d'infirmières, ou encore des méthodes de recherche qui s'orientent de plus en plus vers le choix d'approches naturalistes, fait en sorte que cette discipline se rapproche graduellement du domaine des sciences sociales et tend à prendre une certaine distance des sciences bio-médicales. L'intérêt pour les concepts de stress et de *coping* est dans cette perspective une illustration particulièrement intéressante d'un partage de connaissances et d'une co-fertilisation entre les sciences sociales, en tant que disciplines fondamentales, et les sciences infirmières en tant que discipline professionnelle ou appliquée.

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Revue canadienne de recherche en sciences infirmières

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Volume 28 – 1996

The Canadian Journal of Nursing Research is indebted to the persons below who served as reviewers for Volume 28. They gave generously of their time and 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 28. Ces personnes ont généreusement donné de leur temps et ont partagé leur savoir. Ce faisant, elles ont largement contribué au processus éditorial et au développement des connaissances en sciences infirmières.

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Call for Papers

Loss & Bereavement

Winter 1997 (vol. 29, no. 4)

Manuscripts are invited that address issues related to loss and bereavement. Topics such as individual and family response to a variety of losses and new approaches to care are welcome. Preference will be given to research reports, especially those which give direction for utilization of findings in practice. However, thought or review papers dealing with ethical, legal, educational, and professional issues related to loss and bereavement are also invited.

Guest Editor: Dr. Betty Davies

Submission Deadline: June 15, 1997

Systems Research

Spring 1998 (vol. 30, no. 1)

The aim of this issue is to make a contribution to our knowledge of nursing and/or patient-care systems and their application to the organization, delivery, and evaluation of care. Topics with potential for enhancing the development and implementation of information systems as well as reports of testing and implementation are of particular interest.

Guest Editor: Dr. Phyllis Giovannetti

Submission Deadline: September 15, 1997

Please send manuscripts to:

The Editor
Canadian Journal of Nursing Research
McGill University School of Nursing
3506 University Street
Montreal, QC H3A 2A7
Canada

Articles à publier

La perte et le deuil

Hiver 1997 (vol.29, no. 4)

On demande des manuscrits traitant des questions liées à la perte et au deuil. Les sujets tels que les réactions individuelle et familiale aux diverses pertes et les nouvelles méthodes pour ce qui a trait aux soins sont particulièrement les bienvenus. On recherche surtout des textes qui donnent une orientations pour l'utilisation des résultats dans la pratique. Cependant, on accueillera favorablement tout article de fond ou de synthèse traitant des questions déontologiques, juridiques, pédagogiques et professionnelles liées à la perte et au deuil.

Rédactrice invitée: D^{re} Betty Davies

Date limite pour les soumissions: le 15 juin 1997

La recherche sur les systèmes

Printemps 1997 (vol.30, no. 1)

L'objectif du présent numéro est de participer à l'approfondissement de la connaissance en sciences infirmières sur les différents systèmes de soins prodigués aux usagés ainsi que leur mis en pratique au niveau de l'organisation, de la prestation et de l'évaluation des soins. On recherche surtout les sujets qui permettraient d'améliorer le développement et la mis en place de systèmes d'information ainsi que des études d'utilisation et d'implantation de tels systèmes. Ces sujets présentent un très grand intérêt.

Rédactrice invitée: D^{re} Phyllis Giovannetti

Date limite pour les soumissions: le 15 septembre 1997

Prière d'envoyer les manuscrits à :

La rédactrice en chef

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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 8 1/2" 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*, School of Nursing, 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 name(s), 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 a summary of the argument.

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La *Revue canadienne de recherche en sciences infirmières* paraît quatre fois par année. Son mandat est de publier la recherche en sciences infirmières qui a trait au développement des connaissances dans la discipline et l'analyse de la mise en pratique de ces connaissances. La revue accepte également des articles de recherche reliés à l'éducation, à l'histoire de même que des articles reliés à la méthodologie, la théorie et l'analyse critique qui permettent le développement des sciences infirmières. Des lettres et commentaires sur des articles publiés son également encouragés.

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