



NURSING PAPERS PERSPECTIVES EN NURSING

Issues in Coping Research

Coping with the Birth of an Anomalous Infant

Sick/Well Self-concept Adaptations in
Adults with Diabetes

Factors Influencing Dietary Adherence as Perceived
by Patients on Long-term Intermittent
Peritoneal Dialysis

Schizophrenia and the Effect of Patient Education

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CONTENTS — TABLE DES MATIÈRES

2 Editorial

5 Issues in Coping Research

Résumé: Recherches sur les façons de composer

L. Joan Brailey

14 Coping with the Birth of an Anomalous Infant

Résumé: Comment composer lors de la naissance d'un enfant anormal

Pushpa Butani

26 Sick/Well Self-concept Adaptations in Adults with Diabetes

Résumé: L'adaptation au concept de soi des adultes atteints de diabète

Diana Gendron

38 Factors Influencing Dietary Adherence as Perceived by Patients on Long-term Intermittent Peritoneal Dialysis

Résumé: Facteurs influençant l'adhésion à un régime: perception des sujets soumis à une dialyse péritonéale intermittente à long terme

Margaret R. Hume

55 Schizophrenia and the Effect of Patient Education

Résumé: La schizophrénie et l'éducation des patients

Elizabeth A. McCay

71 Information for Authors

72 Renseignements à l'intention des auteurs

EDITORIAL

This issue of *Nursing Papers* is co-sponsored by the University of Toronto Faculty of Nursing. The authors who publish in the following pages are members of the Faculty of Nursing, University of Toronto. We are pleased to again use this means of reaffirming the importance of this journal to nursing and to the development of the discipline of nursing. As a refereed journal with high and rigorous standards it is a precious resource for vital communication among nurses in Canada and beyond, communication that is essential to the growth and testing of knowledge for the practice of nursing.

A Faculty editorial committee, chaired by Professor Kathleen King, gave leadership in identifying the theme, in providing the stimulus for the development of papers and in using the established processes of the Review Board and Editor of *Nursing Papers*. The work of this committee is appreciated.

The thread which unifies the varied papers in this and in an ensuing issue is "coping with and adaptation to health-related issues," a theme which to this Faculty has long been of interest as central to nursing in its task of assisting people to use their own resources in attaining, maintaining and retaining health. This collection of papers reflects a variety of manifestations of this interest as well as a range of human responses to health problems. Butani draws on literature to consider how parents can be assisted in coping with the stress of the arrival of an infant with birth anomaly, while Gendron examines self-concept in relation to diabetes as the stressor, suggesting some implications for nursing. Hume provides findings from an investigation of dietary adherence of a small sample of patients on peritoneal dialysis. McCay reports a pilot study involving schizophrenic patients and the effect of patient education on their health knowledge and beliefs, fundamental to coping with their health problem. In the area of researching coping repertoires and their effectiveness, Brailey identifies and discusses a number of questions of methods, considerations which are vital to the tasks ahead in building the knowledge required for understanding the phenomena associated with coping with and adapting to health related problems.

We hope that these papers serve to further dialogue, study and testing in this important area of coping with and adaptation to health-related issues.

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ÉDITORIAL

Ce numéro de *Perspectives en nursing* est publié en collaboration avec la faculté des sciences infirmières de l'université de Toronto, dont les auteurs des différents articles font partie. Nous sommes heureux d'utiliser à nouveau cette voie pour réaffirmer l'importance que *Perspectives en nursing* représente pour les sciences infirmières et le développement de cette discipline. Avec son comité de lecture et ses normes élevées et très rigoureuses, cette revue constitue un instrument précieux de communication pour les infirmières du Canada et de l'étranger, instrument indispensable au développement et à la vérification des connaissances qui permettent d'exercer ce métier.

Un comité de rédaction présidé par le professeur Kathleen King, a décidé de l'orientation du thème, a fourni l'impulsion voulue pour produire des articles et a veillé à l'emploi des procédés établis par le comité de lecture et par la rédaction de *Perspectives en nursing*. Les travaux de ce comité sont fort précieux.

Le thème commun aux divers articles de ce numéro et d'un numéro à paraître est: "comment composer avec les problèmes liés à la santé et comment s'y adapter"; c'est un thème qui suscite l'intérêt de notre faculté depuis longtemps car il est au centre des sciences infirmières, en ce sens qu'il vise à aider les gens à utiliser leurs propres ressources pour améliorer leur état de santé, le maintenir et le conserver.

Ce recueil d'articles reflète diverses manifestations de cet intérêt ainsi que tout un éventail de réactions humaines devant les problèmes de la santé. Butani fait une analyse des écrits parus pour savoir comment aider les parents à faire face au stress que provoque l'arrivée d'un nouveau-né souffrant d'anomalies, tandis que Gendron examine le concept de soi par rapport au diabète en tant que facteur stressant, ce qui a des implications pour les sciences infirmières. Hume nous livre les résultats d'une enquête sur l'adhésion à leur régime par un petit échantillon de sujets soumis à une dialyse péritonéale. McCay rend compte d'une étude pilote qui met en jeu des patients schizophrènes et parle des effets de l'éducation de ces patients sur leurs connaissances et leurs croyances en matière de santé. Brailey aborde un certain nombre de questions d'ordre méthodologique qui sont de première importance à quiconque veut acquérir les connaissances nécessaires pour comprendre les phénomènes liés aux diverses façons de composer avec les problèmes de santé et de s'y adapter.

Nous espérons que ces articles serviront à approfondir le dialogue, l'étude et la vérification de cet important domaine que constituent les façons de composer avec les problèmes de santé et de s'y adapter.

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NURSING RESEARCH: A BASE FOR PRACTICE

The Proceedings of the 9th National Nursing Research Conference held in Montreal on October 12, 13 and 14, 1983 are now available at the price of \$30 (over 575 pages).

Nursing Papers subscribers are invited to place their order using the enclosed order form with the Managing Editor, *Nursing Papers*.

LA RECHERCHE INFIRMIÈRE AU SERVICE DE LA PRATIQUE

Les Actes du 9e Colloque national de recherche en sciences infirmières tenu à Montréal les 12, 13 et 14 octobre 1983 sont maintenant disponibles au prix de 30\$ (plus de 575 pages).

Les abonnés de *Perspectives en nursing* sont invités à placer leur commande auprès de l'adjointe administrative à la rédaction de *Perspectives en nursing*. Un bon de commande est inclus à cette fin.

ISSUES IN COPING RESEARCH

L. Joan Brailey

Study of the patterning of human behaviour in interaction with the environment has been identified as a major theme for nursing research (Donaldson & Crowley, 1978). The processes of coping with the stresses of everyday living form an important part of this patterning yet to date little research has been conducted in this area. The need for careful study of the nature and substance of people's coping repertoires in everyday life situations and the relative effectiveness of different ways of coping has been repeatedly cited (Folkman & Lazarus, 1980; Kanner, Coyne, Schaefer, & Lazarus, 1981; Mechanic, 1974; Pearlin & Schooler, 1978). Such investigations are needed to provide information about effective strategies for avoiding or reducing stress in order to assist people to attain or maintain high levels of wellness. Although coping with illness is also an important area of nursing study it will not be addressed in this paper.

During the planning of an investigation of the coping strategies used by mothers of preschool children in stressful events in their daily lives, many difficult research issues related to the study of coping efficacy became apparent. This paper will consider three research issues in relation specifically to studying effectiveness of coping strategies used in everyday life situations. Firstly, in order to study effectiveness of coping, we must be able to obtain an accurate picture of how people actually do cope with stressful events or situations in their daily lives. Four methods of data-collection will be described and weaknesses of each noted. Secondly, in order to determine effectiveness of coping, researchers and theorists must be able to delineate clearly the functions of coping. We cannot determine whether strategies are effective or not unless we are able to state the goals or purposes of coping efforts. Finally, once we have a clear idea of the functions of coping and valid data regarding coping strategies usually used, researchers must decide on ways to measure the efficacy of strategies used in fulfilling the stated functions. Each of these issues will be addressed in turn.

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COLLECTING DATA ABOUT COPING STRATEGIES USED

At least four different methods of collecting data about coping behaviours of healthy individuals with the stressful events of everyday life have been utilized by researchers in recent years. Each method has some drawbacks. One method is direct observation by the researcher of the subject while he is coping with "normal" events. Murphy and her colleagues (Murphy & Moriarty, 1976) conducted an 18-year longitudinal study of children's coping behaviours in actual stressful situations. Such a method yields very rich data but is expensive and time consuming and thus is infrequently used. The presence of an observer may also alter the situation and responses.

A second method of data collection is obtaining subject responses to vignettes of stressful situations or episodes. In 1969, Sidle, Moos, Adams and Cady developed an easily scorable scale with which to assess general coping strategies of everyday life. The questionnaire included three problem situations for each of which the subject was to rate ten listed coping strategies on a seven-point scale in terms of how likely he would use it in that situation. Subjects were also asked for open-ended, free responses regarding the coping strategies they would use in each situation. The investigators concluded that a pencil and paper measure is capable of eliciting information about even less socially approved ways of coping.

Other investigators have also used the vignette method in studying the coping strategies used by intensive care nurses (Jacobson, 1983; Oskins, 1979) and mothers of toddlers (Rourke, 1982). The drawback to this method is that even with careful validation of the appropriateness of the vignettes, the episodes may not represent situations realistic for or considered stressful by the respondents.

The third method for collecting data about coping behaviour is to ask respondents how they *usually* cope with *general* sources of stress in their lives. Investigators have used this method to carry out a major study of the ordinary stresses people encounter in everyday life and the ways they cope with these stresses (Pearlin & Schooler, 1978); to compare the coping methods used by psychiatric patients and persons with no history of psychiatric illness (Bell, 1977); to compare the coping behaviours of emergency room patients and newly diagnosed hypertensive patients (Jaloweic & Powers, 1981); and to investigate the coping behaviours reported by college students as used in response to stresses of undergraduate student life (Tanck & Robbins, 1979; Ziemer, 1982). The studies by Bell, Jaloweic and Powers, and Tanck and Robbins all used a list of coping responses or strategies on which

the respondent rated himself on a scale of one to five (never to always) as to his likelihood of using each strategy when feeling stress or tension. The weakness inherent in asking respondents how they usually cope with general sources of stress in their daily lives is that there may be a poor relationship between what people say they usually do and what they actually do in specific instances (Folkman & Lazarus, 1980).

Only one study was found which used a fourth method of study, asking respondents to identify specific stressful events which occurred recently in their own daily lives and to report on coping strategies used in relation to those specific events. Folkman and Lazarus (1980) analyzed the ways 100 community-residing men and women aged 45 to 64 coped with specific stressful events of daily living during a one-year period. Information about recently experienced stressful encounters was elicited through monthly interviews. At the end of each interview, the participants indicated on a 68-item checklist those coping thoughts and actions used in each specific stressful encounter.

This method has the very great advantage of using real events regarding which the respondent can state what he actually did or thought. Selective distortion of self-report has been found to be substantially reduced when people are asked what they did in a specific instance rather than how they generally perform (Nelson & Craighead, 1977).

The method could be used with either a cross-sectional or longitudinal research design. The longitudinal design enables the researcher to study the same individuals across situations and over time, thus identifying patterns of coping strategies used. Three disadvantages of this method have been identified. Sometimes respondents have difficulty isolating one specific stressful event or encounter from a build-up of a myriad or small irritants. Secondly, the practice of presenting subjects with a prepared checklist of coping strategies may provide "cues" which influence responses (Ziemer, 1982). Thirdly, in the longitudinal design, the repeated measures of stressful events and coping efforts create a problem of dependency in the data which may lead to inflation of relationships (Folkman & Lazarus, 1980). In spite of these difficulties, it is believed that this fourth method has the greatest advantages in obtaining accurate data about stressful events experienced and coping strategies actually used by the respondents.

FUNCTIONS OF COPING

Which coping strategies are effective? In order to answer this question one must of course ask, effective for what? In turning to con-

sider the functions of coping one finds great disagreement among theorists and researchers.

Lazarus and Launier (1978) write that coping strategies serve two main functions: alteration of the stressful person-environment relationship (often referred to as problem-focused coping) and control of the emotional reaction arising from that relationship (often referred to as emotion-focused coping). These two functions are sometimes also referred to as instrumental and palliative functions, respectively. Lazarus considers both these functions as important in coping (Lazarus & Launier, 1978). As well as lessening the person's distress, the emotion-focused strategies may improve the individual's ability to subsequently handle the problem or stressor itself in a constructive way.

Pearlin and associates (1978, 1981) delineate three major types of coping that are distinguished from one another by the nature of their functions. These are: 1) responses that change the situation out of which strainful experience arises; 2) responses that control the meaning of the stressful experience after it occurs but before the emergence of stress; and 3) responses that function more for the control of emotional distress itself after it has emerged. Pearlin and Schooler (1978) refer to coping efforts serving the second function as by far the most common type of individual coping and give as examples: making positive comparisons with the experience of others; selective ignoring; and hierarchical ordering of areas of one's life by which one downplays difficult areas. Thus, by cognitively neutralizing the threats that we experience in life situations, it is possible to avoid stresses that might otherwise result.

Others disagree with Lazarus and Pearlin on the importance of the palliative function of coping. They differentiate between coping and defending. According to Weisman & Worden (1976-77) coping involves the individual's taking active measures to resolve the problem confronting him. If the problem is resolved, then the individual will have coped effectively with it. In contrast, the function of defending is the relief of the individual's distress through avoidance or denial of the problem, not its resolution (Weisman & Worden, 1976-77). In White's (1974) view defence mechanisms are strategies of adaptation and work effectively in the short range by making anxiety bearable, but he argues that in the long run they are not adaptive as they prevent the individual from learning about the situation and achieving some mastery over it.

In rebuttal, Roskies and Lazarus (1980) point out that there has been a tendency to downgrade intrapsychic and palliative modes of coping because of their traditional association with pathology and self-deception. Yet they emphasize that as the cognitive behaviour therapists have so vividly demonstrated in the past few years, changing how a person thinks and feels in a situation can be extremely effective in helping to cope with the situation. With such divergence of opinion on the functions of coping, evaluation of effectiveness of coping behaviours must be based on the particular viewpoint of the functions of coping that one assumes.

MEASUREMENT OF COPING EFFICACY

The study of coping in everyday life situations would not be complete without measurement of the efficacy of the coping efforts. Information is needed about effective coping strategies in order to intervene with clients in prevention, treatment or education regarding coping with stress. As previously discussed, measurement of coping effectiveness must be guided by the designated functions of coping but other difficult questions arise as well. Roskies and Lazarus (1980) believe that neither clinicians nor researchers have seriously addressed themselves to the issue of evaluation of coping efforts.

One important question relates to the time chosen for judging efficacy of coping efforts. Menaghan (1982) points out that conclusions about effectiveness may depend entirely on the time frame used for evaluation. Strategies that are effective in the short-term may not be effective for well-being if they are continued for a period of years.

Another important question to be addressed is the unit of evaluation: individual coping strategies or patterns of strategies used in sequence. Pearlin and Schooler (1978) argue that perhaps effective coping depends not only on what we do, but also on how much we do. "The single coping response, regardless of its efficacy, may be less effective than bringing to bear a range of responses to life strains" (p. 13). Monat and Lazarus (1977) also agree that combinations of strategies may be important.

A third question related to measuring the effectiveness of coping is: who should make the judgment? Some investigators have asked respondents what coping strategies worked best for them (Berman & Turk, 1981; McCubbin, Dahl, Lester, Benson, & Robertson, 1976). Other researchers (Menaghan, 1982) are critical of reliance on respondents' claims that a strategy or approach was helpful to them in

some way, preferring more objective measures of effectiveness. Surely if each person is viewed as a unique individual who is striving toward an increasingly higher level of well-being and self-actualization, coping efforts should be subjectively defined and evaluation necessarily at least partly subjective.

The major question related to evaluation of coping efficacy however relates to the criteria which should be used. Some investigators use theoretical criteria to identify appropriate, adequate or mature coping efforts. For example, Haan (1977) conceptualizes coping in terms of ego processes, ranking ego processes as fragmentation, defence or coping according to their adherence to an objective reality. Antonovsky (1979) proposes the criteria of flexibility, far-sightedness and rationality for evaluating the overall maturity of coping styles. Bell (1977) categorized coping strategies used as short-term or long-term implying the superior value of the long-term strategies. Coping methods were divided into long and short-term methods based on the investigator's view of the "reality-oriented, constructive effect each would have in dealing with stress for a long duration of time" (p. 319). Thus value judgments have been tied to the evaluation of coping efforts. These theoretical notions need to be empirically tested to determine actual effectiveness.

Other theorists and researchers have stressed the importance of outcome measures of coping effectiveness. Hamburg and Adams (1967) highlight the following four far-reaching standards in judging effectiveness of coping efforts: 1) how well the personal distress is relieved; 2) how well the sense of personal worth is maintained; 3) whether the coping strategy allows for rewarding continuity of interpersonal relationships; and 4) how well the requirements of the stressful tasks are met.

Pearlin and Schooler (1978) agree that the effectiveness of coping behaviour should be judged on outcome criteria. They state that effectiveness cannot be judged solely on how well the coping strategies purge problems and hardships from our lives, but also how well the coping efforts prevent these hardships from resulting in emotional distress. In their research (Pearlin & Schooler, 1978) they have used a single criterion for weighing coping efficacy: "simply the extent to which a coping response attenuates the relationship between the life strains (stressors) people experience and the emotional stress they feel" (p. 8).

Lazarus and associates (Roskies & Lazarus, 1980) state that coping behaviour can be evaluated along two dimensions: a) the effectiveness

with which a task is accomplished and (b) the cost of this effectiveness to the individual. The cost to the individual is further separated into two components: a) the physiological cost of harmful disturbance in body homeostasis and b) the psychic cost of violation of value integrity. Thus coping behaviour may be said to be effective when a task is accomplished according to standards tolerable to the individual and the group in which he lives.

Lazarus (1981) believes then that coping effectiveness can only be judged by the outcome in morale, social functioning and somatic health. He and his colleagues have concern though about the prematurity of attempts to assess outcomes of coping until there is a workable approach to the measurement of coping and at least a "preliminary understanding of the consistency of the coping process across stressors and some of the determinants of coping" (Folkman & Lazarus, 1980, p. 220). Lazarus points out that answers regarding effectiveness may vary with the kind of person and the context of the situation, and depend on the respondent's personal values. "Optimal functioning might mean that all three categories of adaptational outcome, namely, social functioning, morale and somatic health, be in harmony in the ideal case. The trouble is that some coping strategies may work well for one value, say, morale, but poorly in generating effective instrumental actions" (Lazarus, 1981, p. 210). For example, yelling at a child or spanking a child who 'misbehaves' may relieve the mother's tension but may not help the mother and child to devise comfortable ways of co-existing in the home or to promote the child's optimal development.

It may be impossible to make a global judgment of effectiveness. If coping has more than one function, it may be impossible to consider all functions simultaneously, but it may be necessary to make several measurements of aspects of effectiveness: perhaps measuring reduction in individual's subjective distress when faced with problems plus reduction of the problem or stressor itself. The latter would have to be measured over time. In addition it may be important to focus on the effectiveness of coping patterns or constellations of coping strategies used as well as individual coping strategies. Finally, it may be important to include outcome measurement of the individual's morale, social functioning and somatic health.

CONCLUSION

Both the study and teaching of coping are necessarily based on ability to distinguish effective from ineffective coping. This paper has raised some of the issues that need to be addressed regarding the

measurement, functions and evaluation of coping responses to the events of everyday life. It is only through the discussion of and research into such issues that a body of knowledge will be developed which can be used to facilitate people's coping with stressful events of life in order to achieve a high level of wellness and self-actualization. Once the effectiveness of particular coping behaviours is established, we can then move on to identify how these behaviours can be promoted in individuals who encounter stress.

REFERENCES

- Antonovsky, A. *Health, stress, and coping*. San Francisco: Jossey-Bass, 1979.
- Bell, J. Stressful life events and coping methods in mental illness and wellness behaviors. *Nursing Research*, 1977, 26, 136-141.
- Berman, W. H., & Turk, D. C. Adaptation to divorce: Problems and coping strategies. *Journal of Marriage and the Family*, 1981, 43, 179-189.
- Donaldson, S. K., & Crowley, D. M. The discipline of nursing. *Nursing Outlook*, 1978, 26, 113-120.
- Folkman, S., & Lazarus, R. S. An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior*, 1980, 21, 219-239.
- Haan, N. *Coping and defending: Processes of self-environment organization*. New York: Academic Press, 1977.
- Hamburg, D. A., & Adams, J. E. A perspective on coping behavior. *Archives of General Psychiatry*, 1967, 17, 277-284.
- Jacobson, S. F. Stress and coping strategies of neonatal intensive care unit nurses. *Research in Nursing & Health*, 1983, 6, 33-40.
- Jaloweic, A., & Powers, M. J. Stress and coping in hypertensive and emergency room patients. *Nursing Research*, 1981, 30, 10-15.
- Kanner, A. D., Coyne, J. C., Schaefer, C., & Lazarus, R. S. Comparison of two modes of stress measurement: Daily hassles and uplifts versus major life events. *Journal of Behavioral Medicine*, 1981, 4, 1-39.
- Lazarus, R. S. The stress and coping paradigm. In C. Eisdorfer, D. Cohen, A. Kleinman & P. Maxim (Eds.), *Models for clinical psychopathology*. New York: Spectrum Publications, 1981.
- Lazarus, R. S., & Launier, R. Stress-related transactions between person and environment. In L. A. Pervin & M. Lewis (Eds.), *Perspectives in interactional psychology*. New-York: Plenum: 1978.
- McCubbin, H. I., Dahl, B., Lester, G. B., Benson, D., & Robertson, M. L. Coping repertoires of families adapting to prolonged war-induced separations. *Journal of Marriage and the Family*, 1976, 38, 461-472.
- Mechanic, D. Social structure and personal adaptations: Some neglected dimensions. In G. V. Coelho, D. A. Hamburg & J. E. Adams (Eds.), *Coping and adaptation*. New York: Basic Books, 1974.
- Menaghan, E. Measuring coping effectiveness: A panel analysis of marital problems and coping efforts. *Journal of Health and Social Behavior*, 1982, 23, 220-234.

- Monat, A., & Lazarus, R. S. (Eds.). *Stress and coping*. New York: Columbia University, 1977.
- Murphy, L., & Moriarty, A. *Vulnerability, coping and growth*. New Haven, Conn.: Yale University Press, 1976.
- Nelson, R. E., & Craighead, W. E. Selective recall of positive and negative feedback, self-control behaviors, and depression. *Journal of Abnormal Psychology*, 1977, 86, 379-388.
- Oskins, S. L. Identification of situational stressors and coping methods by intensive care nurses. *Heart and Lung*, 1979, 8, 953-960.
- Pearlin, L. I., Lieberman, M. A., Menaghan, E. G., & Mullan, J. T. The stress process. *Journal of Health and Social Behavior*, 1981, 22, 337-356.
- Pearlin, L. I., & Schooler, C. The structure of coping. *Journal of Health and Social Behavior*, 1978, 19, 2-21.
- Roskies, E., & Lazarus, R. S. Coping theory and the teaching of coping skills. In P. Davidson & S. Davidson (Eds.), *Behavioral medicine: Changing health lifestyles*. New York: Bruner & Mazel, 1980.
- Rourke, M. E. *The reported coping strategies of mothers of toddlers in response to stress-related incidents involving toddlers*. Unpublished master's thesis, University of Manitoba, 1982.
- Sidle, A., Moos, R., Adams, J., & Cady, P. Development of a coping scale. *Archives of General Psychiatry*, 1969, 20, 226-232.
- Tanck, R. H., & Robbins, P. R. Assertiveness, locus of control and coping behaviors used to diminish tension. *Journal of Personality Assessment*, 1979, 43, 396-400.
- Weisman, A. D., & Worden, J. W. The existential plight in cancer: Significance of the first 100 days. *International Journal of Psychiatry in Medicine*, 1976-77, 7, 1-15.
- White, R. W. Strategies of adaptation: An attempt at systematic description. In G. V. Coelho, D. A. Hamburg, & J. E. Adams (Eds.), *Coping and adaptation*. New York: Basic Books, 1974.
- Ziemer, M. M. Coping behavior: A response to stress. *Topics in Clinical Nursing*, 1982, 4(2), 4-12.

RÉSUMÉ

Recherches sur les façons de composer

On a établi la nécessité d'étudier soigneusement les façons dont les individus composent avec les problèmes de santé dans les situations quotidiennes de la vie ainsi que l'efficacité de ces différentes façons. Cet article aborde trois grandes questions de recherche ayant trait à ce type d'étude: les méthodes de cueillette de données pour se faire une idée précise de la façon dont les individus composent avec les situations; la délimitation des fonctions des modes d'adaptation; et la mesure de l'efficacité des stratégies utilisées.

COPING WITH THE BIRTH OF AN ANOMALOUS INFANT

Pushpa Butani

Congenital anomalies are caused by a multiplicity of agents, most as yet not known. Although congenital anomalies are not frequent, their occurrence is always traumatic for the whole family. In addition to the usual adjustments related to maturational crisis that occur as a part of the normal process of parenthood, families of anomalous infants have to cope with the superimposed situational crisis.

When an anomalous infant is born, many reactions and adjustments occur. Knowledge and understanding of parental reactions will help the nurse to assess and plan appropriate interventions. This paper will examine the impact that an anomalous infant has on the family and consider ways in which health professionals can enhance a positive adjustment to the crisis of birth of an anomalous infant.

REACTIONS OF PARENTS

The birth of an anomalous infant is always difficult to accept. Expectant parents make a significant material and emotional investment toward the birth of a baby during the course of a normal pregnancy. Couples fantasize their unborn infant as a perfectly healthy copy of themselves. Each parent develops a mental picture of their baby. Each has an idea about the sex, colour of the eyes, hair, complexion and so on.

Although the anticipation is based on the model most desired, a normal child, the literature suggests that no mother is immune to the dreadful possibility that her child may not be normal. The fear of giving birth to an abnormal child is frequently expressed by pregnant women (Caplan, 1959; Goodrich, 1961). When there is a discrepancy between the expectations, hopes and wishes for a normal child, and the reality presented by the anomalous child at birth, the disappointment may be overwhelming, causing emotional trauma for the parents.

It is important for the parents, both psychologically and culturally, to produce a healthy baby. Waechter (1970) states "Our culture sets rigid standards in regard to appearance and intellectual functioning. Perfectly formed, beautiful children represent the societal ideal; therefore, any visible physical defect or intellectual impairment has unique significance as a basis for class and caste distinctions" (p. 205).

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The society in which the parents live will influence the intensity of their feelings toward their anomalous infant.

When an anomalous infant is born the mother may identify with the deformed child and feel personally responsible for the defect. Whenever the diagnosis of a physical or mental defect is made, the reactions of parents are very similar. Certain characteristic behaviours of parents observed are feelings of shock, denial, grief, anger and guilt responses, sadness, anxiety, biological inadequacy and embarrassment varying in intensity and duration (Mercer, 1974; Waechter, 1977; Waisbern, 1980). Parents react to the birth of an anomalous infant with anxiety, depression and low self-esteem regardless of the severity of the infant's abnormality (Murphy, 1982). The sources of the most serious anxiety are the threats to the parents' sense of ego integrity, self-worth and to their social status (Waechter, 1970). It is an emotionally vulnerable time for the family. Because of the emotional tragedy involved, grief reactions and the use of defence mechanisms should not be considered pathological at this time.

Grief

Most parents, professionals and authors cite shock and disbelief as a common normal initial reaction (Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975; Schild, 1971; Wolfensberger & Menolascino, 1970). "The purpose of the shock is to protect the functional ability of the self or ego from what is perceived to be overwhelming threat. Shock insulates the self from alien, unwanted, unacceptable reality allowing that reality to filter through only in manageable amounts" (Sieffert, 1978, p. 35). This reaction may then be followed by a stunned, numbed state characterized by inability to accept the defect of the infant and behaviours such as confusion, disorganization and immobilization.

Great demands are made upon the parents by the birth of a defective child; little time is allowed, however, for them to work through the feeling of loss of the perfect child before they are expected to invest their energies in caring for the unexpected defective infant (Solnit & Stark, 1961). During the mourning period the parents temporarily withdraw from their environment, withdrawing psychic energy from the lost love object in which it had been invested. Withdrawal is only the first step in the ego's attempt to cope with the crisis (Ross, 1964). Mercer (1974) observed withdrawal responses to be high during the first week and again at three months. Parents' concerns focus first on their own needs — what does the anomaly mean to them personally? They need to achieve mastery over their own feelings before they can consider the child's needs and what the defect will mean to it (Mercer, 1974).

Grief and mourning reaction may be delayed in the parents of an anomalous infant for months or even years. Kennedy (1970) quotes Siggins that "Mourning may be postponed if the ego is engaged in some other more consuming task" (p. 411). Kennedy observed variations in grief process between those mothers who were engaged in the care of their infants and those mothers whose infants were not living at home. The question may be raised if the demands of caring for an anomalous infant may encourage the postponement of a grief reaction. On the basis of his research Kennedy (1970) sees emotionally giving up the desired infant and accepting the real infant as consecutive rather than simultaneous processes.

Anger and Guilt

Feelings of anger and guilt are often observed in the parents of anomalous infants. As the shock subsides, a sense of anger grows. The feelings of failure and frustration can produce anger in the parents of anomalous infants. Anger stems from having hopes, wishes and dreams forever destroyed. The anger is initially directed at the infant as the obvious source of the frustration of the hopes and expectations which parents built before its birth. The mere thought of rejecting a defective infant creates intense anxiety in the parents. Acknowledging the rejection of the anomalous infant is most difficult for the parents. Defences are used against these unacceptable feelings (Zuk, 1962). Parents may deny the true focus of their feelings by displacement of anger from the disappointing child to themselves. The mother may experience her anger as a personal guilt. She may blame herself for what has happened to the child. The mother asks repeatedly if the problem is due to something she did or did not do. Every possibility is considered and explored in detail. As one mother said, "I don't know what I did wrong, I am trying to think if I had a cold in the first trimester; Should I have taken that aspirin?" Little things that were not thought about during pregnancy hit with devastating force when an anomalous infant is born. This emotional working through is a necessary part of adjusting to the birth of an anomalous infant.

There may be considerable anger toward the professionals or other members of the family. One woman placed the blame on what she saw as inadequate prenatal care she received. Her comments were, "My doctor did not spend much time with me during my prenatal visits; I was in and out of his office in about five minutes." These statements are expressions of feelings of frustration and hostility.

In some religious groups it is believed that malformations are God's punishment for sins committed. This may arouse guilt feelings in the mother, who searches her memory for some specific act of commission or omission (Lobo & Webb, 1970; Smithells, 1963). The mother asks "Why me? What have I done?" (Winick, 1967). The mother perceives her child's defect as a punishment for some imagined or real behaviour on her part which she felt was bad (Cohen, 1963).

Unresolved parental guilt and anger can result in overprotectiveness or guilty attachment to the defective infant and neglect of other family members (Lobo & Webb, 1970). The mother's unconscious wish that the child had never been born and her death wish for the child are countered by the dynamic opposite reaction which helps her to shift her focus to being overprotective (Ross, 1964). The neurotic devotion of a mother to her defective child is more often an expression of her own needs than a response to her child's needs (Forrer, 1969). Parents need to know that feelings of rejection and death wishes for the child are normal reactions and that acknowledging such feelings reflects a means of coping.

Many variables may influence immediate and long-term adjustment of the parents to their anomalous infant. Maturational and external situational factors influence the normal coping effort. For example, maturational factors are the kind of psychological preparation made by the parents during pregnancy for the coming child and past coping experiences with other major losses. Among the numerous situational factors are the sociological and cultural considerations, family stability, the nature and extent of the deformity, the attitudes of professional personnel at the birth of an anomalous infant, availability of community services, and the degree of energy available to parents to deal with the crisis (Butani, 1974; Waechter, 1977).

HOW NURSES CAN FACILITATE ADJUSTMENT OF PARENTS

Nursing care should be directed first at helping parents cope with their initial shock and reactions to the child's anomaly, and secondly at helping parents to become more comfortable in caring for their newborn infant. Nurses have a unique opportunity for the development of rapport and trust with parents early in their care.

Nurses working in maternity settings should have a knowledge and understanding of parents' reactions as a means of coping with the birth of an anomalous infant. This knowledge will aid the nurse to accurately assess psychosocial needs of the family, provide appropriate early interventions, demonstrate sensitivity along with an attitude of caring and warmth. The understanding and counselling provided by the nurse to the parent can facilitate a more appropriate grieving process and attachment between the parent and the defective child.

With the birth of an anomalous infant many feelings are aroused and the professional personnel must deal with conflicting emotions. Some of the questions that need to be dealt with almost immediately in the delivery room are — who is to tell the parents and how much should they be told? The impact of the birth of an anomalous infant is

so overwhelming for the health care team in the delivery room that the parents can sense that something is wrong.

Most parents prefer to be informed of the baby's condition together. Parents need to share their feelings and support each other (Irvin, Kennel & Klaus, 1982). If possible, the nurse should be present when the physician informs the parents, to reinforce the explanation. It is important that the information given to the parents be consistent. The need to confirm other people's assessments of the infant is greater when conflicting information is given to the mothers (Kikuchi, 1983). The explanations must be kept simple and in the terms that the parents can understand. Lengthy medical explanations should be avoided at this time as parents cannot absorb all the information; they are under a great deal of stress. One mother recalled that after hearing the doctor say the baby was "Mongoloid," she could not remember anything else her physician said. "The word 'Mongoloid' kept ringing in my ears, I could not think or do anything."

One of the first questions a mother asks right after delivery is the condition of the baby. It is important that the parents be told of the baby's condition as soon as possible. In a study to determine how, when, and from whom they first learned about the defect of their infant, 694 mothers of babies with various congenital abnormalities were interviewed (D'Arcy, 1968). The mothers attached great importance to the approach and general attitude of the medical and nursing staff who told them about their babies. The manner of presentation of information has a bearing on how parents will react. At a time of crisis, every word has meaning for the parents. Mothers preferred to be told the truth in simple language, and became very anxious if they were merely told not to worry. Many parents report dissatisfaction about the way they were first told of their child's handicap (Tarran, 1981). Mothers expressed a desire for truth and for an avoidance of over-pessimism or unrealistic optimism. Over-optimistic statements regarding the future of the infant may relieve a professional's tension but do not help parents accept reality (D'Arcy, 1968). Therefore professional personnel should clarify the reality of the child's condition as the parents voice each of their questions and/or fears. This reduces the distortions of perception, thinking and feeling which otherwise may occur. Parents' anxiety makes it necessary to repeat this information since they have difficulty hearing and accepting the news.

Many investigators (Berg, Gilderdate, & Way, 1969; Carr, 1970; Daniels & Berg, 1968; D'Arcy, 1968; Drotar et al., 1975; Tisza, 1962) found that the suffering was greatest for parents when there was a delay in telling them of the defect and in showing the infant to the parents. The parents imagined worse things were wrong than the actual defect. Parents need to know the diagnosis of the baby at the time of birth. During the waiting period, several parents reported a growing conviction that their baby had actually died. Upon finally seeing the child, most of the mothers felt relieved. Some of their comments were: "The idea of it was worse than the actual sight; I wondered what kind of a monster I had produced and when I saw him, he was not a monster; The suspense was worse than knowing." At the same time information overload must be avoided when conveying negative news to the parents. Realistic hope must be given. "Hope increases human strength adding to the personality's usual capacity to cope with stress" (Travis, 1976, p. 19). D'Arcy (1968) emphasizes that "the initial counselling of the mothers of malformed infants makes a deep and lasting impression" (p. 798).

This writer's observations tend to support that parents who have opportunities to see, touch and hold their anomalous child cope effectively with the whole experience. Nurses need to be sensitive and must recognize the cues that the parents wish to see their child. If the baby is badly malformed, the nurse can show the well-formed parts of the body and later show the malformed parts if the parents wish. It is important to move at the parents' pace.

With the birth of an anomalous infant there are usually no celebrations, no rituals or societal supports. There are very few flowers, gifts and cards sent to the hospital after the birth of an anomalous infant. Friends and relatives may not call or visit parents. The parents may be reluctant to send out announcements of the birth. Thus parents may experience intense loneliness during the immediate post-partum period (Irvin et al., 1982). The primary concern of the mothers of anomalous infants is for the social acceptance and support of their babies (Mercer, 1974). Demands are made on parents for providing care to their congenitally deformed infant at a time when they are experiencing emotional trauma and need for psychological support and understanding. In the early post-partum period, the nurse should attend to the mother's own dependency needs; the mother at this time needs love, warmth and acceptance. It is much easier for parents to accept their own feelings if they are accepted by professional people.

The mother has been narcissistically wounded; she may be more regressed and dependent (Waechter, 1970). Parents' sense of self-worth is improved when they see that their child is being valued by the professionals. It is important that such a positive attitude is demonstrated by the nurse right from the beginning. Small acts of kindness are clearly remembered by the parents years after the event.

To facilitate the mourning process the mother needs physical rest to increase the energy level, an opportunity to review her thoughts and feelings about the wished-for child, and a realistic interpretation and investment in the feared and unexpected child. Allowing the parents to ventilate their feelings of hostility, guilt and anxiety may help reduce their anger and leave more energy for caring for their infant.

Initially, it is hard for the parents of a defective infant to hold it, feed it, and begin to relate to the child with cuddling and love. It is not abnormal for a mother to feel repulsed by the child's obvious physical defect or feel resentment toward her anomalous child. These emotions conflict with her natural desire to love the infant. Factors that influence mother-child relationship are the mother's measure of self-esteem, degree of self-acceptance, and the amount of feedback received from the baby (Gordenk, 1976). The mother needs to identify her newborn infant both in appearance and function. She needs to compare the features of her infant with significant others (Rubin, 1961). Rubin (1963) suggests that mothers who have anomalous infants are handicapped in their attainment of the maternal role by their infant's inability to respond normally. This is why parents need help in seeing their child as a little person. It requires time for the parents to learn about their child's characteristics as an individual. The mother needs to be relieved of her feelings of guilt for her lack of motherliness. Parent-infant bonding develops over time and through experiences within the relationship of parent and child. It is important for parents to hear from the health professionals that the feelings they are experiencing are perfectly normal and that the professionals are available to help in any way they can.

Parents need time to adjust but professionals tend to become impatient with the lengthy emotional process which most parents go through with the birth of an anomalous infant and feel the urgency to do something about it (Olshansky, 1962; Sieffert, 1978). Wilker, Wasow and Hatfield (1981) observed chronic sorrow or periodic crisis rather than time-bound adjustment of parents of mentally retarded children. Allowing parents time to proceed at their own pace through the grieving process and in caring for their infant can enhance their

ability to cope. Allowing time to parents does not mean leaving them alone and walking out on them but being available when needed. This further enables the parents to actively participate in the decision-making process regarding the care of the child, thus enhancing their ability to cope with the challenge of having a child with a congenital anomaly (Solnit & Stark, 1961).

The needs of parents of an anomalous infant are extensive and ongoing. The team approach of professionals is required to assist the family. The nurse's responsibility lies in supporting parents in order to reduce their feelings of being overwhelmed and to conserve their energy for coping with the initial impact of the birth of an anomalous infant. Nurses act as role models in caring for the infant. If nurses relate warmly and with sensitivity and handle the infant like any other newborn, they do not only increase the parents' confidence in their own ability but also demonstrate to the parents a social acceptance of their infant. When the parents are ready to get involved in the care of their infant, the nurse should provide encouragement and compliment them on their achievements. The nurse can influence the relationship between the anomalous infant and the family, which in turn will affect the child's self-concept. The nurse can assist parents in the process of becoming more confident and competent in caring for and relating with their newborn. As the mother becomes more comfortable with the physical care of her baby, she may feel less threatened, less anxious and she will have more energy to cope with other tasks. This in turn will increase the parents' self-esteem, which is a major factor in the development of the maternal role. It is essential for parents to recognize their infant's strengths, however limited they might be. It is through the professional's emphasis on these strengths and positive behaviours of the infant that parents gain confidence in trusting their own positive feelings and expectations for their child's growth (Howard, 1982).

In order to facilitate the family's adjustment to having a child with an anomaly, the nurse needs to demonstrate an understanding of the feelings of parents about their anomalous infant. It is necessary to determine the concerns of the parents so that appropriate support can be given to maximize parental coping. The nurse needs to assess the family strengths and utilize family support to enhance parental coping. Parents' mutual support of each other after the birth will facilitate a positive long-term acceptance of the child (Drotar et al., 1975).

The nurse may find it difficult to work with angry parents, especially when the anger is vented on the nurse or other health professionals. However, when one understands that parental anger is directed at their own plight it becomes easier to work with the parents. An important role of the nurse is to listen to the parents' responses, to utilize the skills of therapeutic listening and observation. The nurse needs to establish an atmosphere of trust and confidence which enables parents to express their fearful questions and concerns. There are no answers to many questions but parents need to raise these questions. Parents who can openly ask questions and express concerns about their child's anomaly will be able eventually to make a positive adjustment to the birth of an anomalous infant (Howard, 1982).

If the infant is going to be hospitalized over an extended period of time or will require surgery to correct the defect, the parents need explanation regarding the nature of the defect, the overall treatment procedures, approximate times of surgery and explanations of surgical procedure and prognosis for the infant.

Nurses working in speciality clinics such as birth defects clinics provide nursing assistance for the infant and support for the family. They share their concerns with other involved professionals in assisting the family to cope with the tragic fact (Bennett, 1982).

Public health nurses, through collaboration with other disciplines and community agencies, can provide a consistent and co-ordinated support for the family. They assist the parents to cope in the day-to-day practical difficulties that parents may encounter in caring for their anomalous infant. Close follow-up of the family is recommended during the first three months after the birth of an anomalous infant (Mercer, 1974). Parents need to be informed about community resources, agencies and organizations that provide assistance to handicapped children, and that self-help groups offer parents a place to go and share their problems with others who are encountering similar experiences. Identification of available resources is often crucial in resolving the emotional turmoil of parents. Referral to the social worker for consistency and continuity of care is important. The social worker can help to co-ordinate medical and emotional support for the family after discharge from the hospital. Through time, ongoing care and support systems, parents learn to cope with the numerous tasks expected of them at this time of crisis.

It is the view of this writer that an understanding and compassionate nurse can make the difference in helping the parents cope with such an emotional experience. Nurses who are aware of their feelings and values and understand the reactions of parents to such a tragedy will be able to demonstrate a caring attitude and respect for the parents of an anomalous infant at a time when they are faced with such an emotional experience. This contribution is essential for the positive adjustment of parents to the birth of an anomalous infant.

REFERENCES

- Bennett, F. C. The pediatrician and the interdisciplinary process. *Exceptional Children*, 1982, 48, 306-314.
- Berg, J. M., Gilderdate, S., & Way, J. On telling parents of a diagnosis of mongolism. *British Journal of Psychiatry*, 1969, 115, 1195-1196.
- Butani, P. Reactions of mothers to the birth of an anomalous infant: A review of literature. *Maternal-Child Nursing Journal*, 1974, 3(1), 59-76.
- Caplan, G. *Concepts of mental health and consultation: Their application in public health social work*. U.S. Department of Health, Education, and Welfare, Welfare Administration, Children's Bureau, 1959.
- Carr, J. Mongolism: Telling the parents. *Developmental Medicine and Child Neurology*, 1970, 12, 213-221.
- Cohen, P. C. The impact of the handicapped child on the family. *Social Casework*, 1962, 43, 137-142.
- Daniels, L. L., & Berg, C. The crisis of birth and adaptive patterns of parents of amputee children. *Clinical Proceedings Children's Hospital*, 1968, 24(4), 108-117.
- D'Arcy, E. Congenital defects: Mothers' reactions to first information. *British Medical Journal*, 1968, 27, 796-798.
- Drotar, D., Baskiewicz, A. Irvin, N., Kennell, J., & Klaus, M. The adaptation of parents to the birth of an infant with a congenital malformation: A hypothetical model. *Pediatrics*, 1975, 56, 710-717.
- Forrer, G. R. The mother of a defective child. *The Psychoanalytic Quarterly*, 1969, 28, 59-63.
- Goodrich, F. W. Psychosomatic aspects of obstetrics. *Psychosomatics*, 1961, 195-198.
- Gordenk, A. Motherhood and a less than perfect child: A literature review. *Maternal-Child Nursing Journal*, 1976, 5(2), 57-68.
- Howard, J. The role of the pediatrician with young exceptional children and their families. *Exceptional Children*, 1982, 48, 316-322.
- Irvin, N. A., Kennell, J. H., & Klaus, M. H. Caring for the parents of an infant with a congenital malformation. In M. H. Klaus & J. H. Kennell (Eds.), *Parent-Infant Bonding* (2nd ed.), St. Louis: Mosby, 1982.
- Kennedy, J. F. Maternal reactions to the birth of a defective baby. *Social Casework*, 1970, 51, 410-416.

- Kikuchi, J. *Maternal adaptive responses to hospitalized newborn infants with congenital defects*. Paper presented at a three-day colloquium, The integration of the physically disabled into community living, sponsored by the Faculty of Social Work, University of Toronto, Feb. 1983.
- Lobo, E. D., & Webb, A. Parental reactions to their mongol baby. *The Practitioner*, 1970, 204, 141-148.
- Mercer, R. T. Responses of mothers to the birth of an infant with a defect. *ANA Clinical Sessions*, 1974, 340-349.
- Murphy, M. A. The family with a handicapped child: A review of the literature. *Journal of Developmental and Behavioral Pediatrics*, 1982, 3(2), 73-82.
- Olshansky, S. Chronic sorrow: A response to having a mentally defective child. *Social Casework*, 1962, 43, 190-193.
- Ross, A. *The exceptional child in the family*. New York: Grune & Stratton, 1964.
- Rubin, R. Basic maternal behaviour. *Nursing Outlook*, 1961, 9, 683-686.
- Rubin, R. Maternal touch. *Nursing Outlook*, 1963, 11, 828-831.
- Schild, S. Counseling services. In R. Koch & J. C. Dobson (Eds.), *The mentally retarded child and his family: A multidisciplinary handbook*. New York: Bruner/Mazel, 1971.
- Sieffert, A. Parents' initial reactions to having a mentally retarded child: A concept and model for social workers. *Clinical Social Work Journal*, 1978, 6(1), 33-45.
- Smithells, R. H. *The early diagnosis of congenital abnormalities*. London: Cassel, 1963.
- Solnit, A. J., & Stark, M. Mourning and the birth of a defective child. *The Psychoanalytic Study of the Child*, 1961, 16, 523-537.
- Tarran, E. Parents' views of medical and social work services for families with young cerebral palsied children. *Developmental Medicine and Child Neurology*, 1981, 23, 173-182.
- Tisza, V. B. Management of the parents of the chronically ill child. *American Journal of Orthopsychiatry*, 1962, 32(1), 53-59.
- Travis, G. *Chronic illness in children: Its impact on child and family*. California: Stanford University Press, 1976.
- Waechter, E. H. The birth of an exceptional child. *Nursing Forum*, 1970, 9, 202-216.
- Waechter, E. H. Bonding problems of infants with congenital abnormalities. *Nursing Forum*, 1977, 16, 298-318.
- Waisbern, S. Parents reaction after the birth of a developmentally disabled child. *American Journal of Mental Deficiency*, 1980, 84, 345-351.
- Wilker, L., Wasow, M., & Hatfield, E. Chronic sorrow revisited: Parents vs. professional depiction of the adjustment of parents of mentally retarded children. *American Journal of Orthopsychiatry*, 1981, 51(1), 63-70.
- Winick, M. Comprehensive approach to a child with a birth defect. *Bulletin of the New Yorker Academy of Medicine*, 1967, 43, 819-828.
- Wolfensberger, W., & Menolascino, F. J. A theoretical framework for the management of parents of the mentally retarded. In F. J. Menolascino (Ed.), *Psychiatric approaches to mental retardation*. New York: Basic Books, 1970.
- Zuk, G. H. The cultural dilemma and spiritual crisis of the family with a handicapped child. *Exceptional Children*, 1962, 28, 405-408.

RÉSUMÉ

Comment composer lors de la naissance d'un enfant anormal

La naissance d'un enfant anormal est un événement traumatisant pour toute la famille. Les parents sont aux prises avec l'anxiété et la dépression et leur estime de soi diminue considérablement, quelle que soit la gravité de l'anomalie dont souffre le nouveau-né. Les besoins des parents sont nombreux et constants. L'infirmière a besoin de connaître et de comprendre les réactions des parents pour être en mesure de les aider. L'appui d'une infirmière compréhensive peut avoir un effet bénéfique sur la capacité d'ajustement des parents suite à la naissance d'un enfant anormal. Le rôle de l'infirmière consiste à aider les parents à faire face à cette naissance avec le minimum de douleur et de souffrance. Pour y parvenir, il faut aider les parents à prendre soin de leur enfant avec confiance et à accroître leur estime de soi.

SICK/WELL SELF-CONCEPT ADAPTATIONS IN ADULTS WITH DIABETES

Diane Gendron

The focus of this paper is on the self-concept related to being sick or being well in adults with diabetes. What will be discussed is one portion of the adaptive task, "preserving a satisfactory self-image" (Moos & Tsu, 1977, p. 9). Many of the ideas expressed apply to people with a variety of chronic illnesses, but the particular application in this paper is to those with diabetes.

CONCEPTUAL FRAMEWORK

It is indicated by Bateson (1979) in a striking passage that the self-concept is determined by the ideas one has:

The mind contains no things, no pigs, no people, no midwife toads, or what have you, only ideas . . . information about 'things' . . . It follows that the boundaries of the individual, if real at all, will be, not spatial boundaries, but something more like the sacks that represent *sets* in set theoretical diagrams or the bubbles that come out of the mouths of the characters in comic strips. (p. 132)

In line with this thinking, the author has developed one listing of various dimensions of a person's being which seem a range of *possibilities* an individual may include in his conception of being sick and being well (Figure 1). These dimensions are derived from personal observations in combination with definitions in the literature, particularly the University of Toronto Faculty of Nursing Conceptual Framework (1981) and Parsons (1958); sociological and anthropological distinctions as described by Ahmed, Kolker and Coelho (1979) and Fabrega (1979); and Smith's (1979) description of health in four categories: clinical, role performance, adaptive ability, and general well-being and self-realization. People vary in how many of the dimensions in the chart they implicitly use as criteria to think of themselves as sick or as well.

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Concept	Well	Sick
Biological Nature		
Physiological Function and Structural Organization	Intact patterns and structural organization	Abnormality in patterns and/or structural organization ("disease" as per Ahmed et al. and Frabega, 1979)
Cognitive-Affective Nature		
Symptom Perception	Asymptomatic, comfortable	Symptoms present, e.g., fatigue, discomfort, hypoglycemic symptoms, decreased vision, paresthesias
Affect	Feeling of well-being	Unhappy, depressed, or anxious
Life Process		
Lifestyle	Lifestyle congruent with that desired by individual	Inability to continue in desired lifestyle
Self-Realization	Fulfilling life goals and growth of self	Impeded from realization of life goals and growth of self
Reciprocal Interaction		
Role Functioning (as per Parsons, 1958)	Ability to carry out all usual role functions	Inability to carry out usual role functions
	Autonomy and independent achievement	Legitimized dependency
	Role vis-à-vis health/illness: to prevent illness	Role vis-à-vis health/illness: to get well
Adaptive Ability	Able to adapt to changing circumstances	Impairment in adaptation
Wholeness	Feelings of integrity, unity	Feelings of conflict, lack of integration, diffuseness

Figure 1. Dimensions of being well and being sick.

In the chart the dimensions of sickness and wellness have been categorized according to the five high-level concepts related to Man in the Conceptual Framework of the University of Toronto Faculty of Nursing. This framework was described originally by Arpin and Parker (1976) and revised in 1981. The five concepts used as categories are Man's wholeness, his cognitive-affective nature, reciprocal interaction, life process and biological nature. The author has placed these concepts in a mandala-like diagram (Figure 2) which indicates their interdependent nature, the stance taken in the conceptual framework that "Man is a whole composed of parts with the whole being more than the sum of the parts" (p. 2), and the interaction of a diabetic person with others, e.g., health care workers, family and friends, or other diabetics. The total of these interactive relationships is beyond the scope of a short paper. The dotted lines in the diagram identify those relationships which are discussed: how selected aspects of the diabetic's pre-existing cognitive-affective nature, life process, and reciprocal interaction affect his self-concept as being sick or being well.

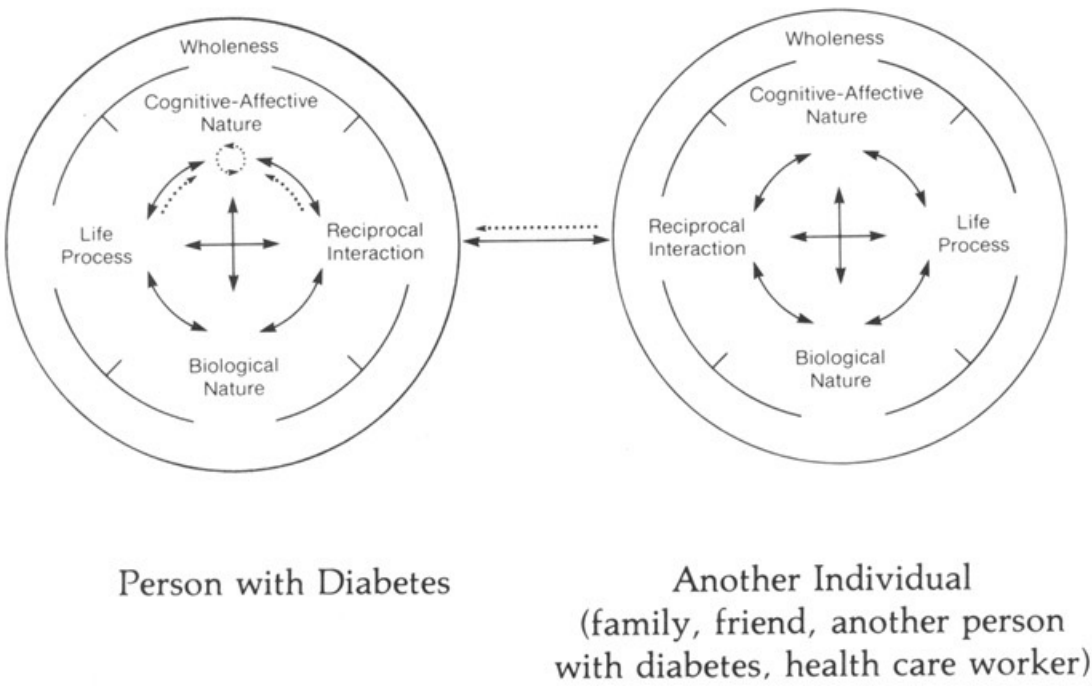


Figure 2. Interactive nature of the high-level concepts of man (University of Toronto Faculty of Nursing, 1981). The dotted lines indicate the relationships discussed in the present paper.

DISCUSSION

Conceptions of Sickness and Wellness

In this paper sick and sickness are used synonymously with illness, and well and wellness with health. The way sickness and wellness are described objectively by various authors may not be the way some individuals with diabetes conceive of themselves in relation to these terms, as the author has found. With some exceptions, health professionals generally view health and illness as a continuum in which elements of both may co-exist. Many laymen, however, seem to think of themselves subjectively as either sick or well, at any one point in time and in a basic way over time.

The concepts of a chronic disease role and of self-care in chronic illness have been receiving increasing attention in recent years. However, it can be seen in the wry (albeit exaggerated) comments of a lay consultant for people with diabetes, that their own perception of being sick or well is often dichotomous and can be confusing:

Often diabetics ask me "Am I sick or am I well? I can't fly a plane, buy insurance, have a baby, or drink two martinis — I'm handicapped! But I'm told I can live a normal life, I look good, feel good, and vocational rehabilitation won't help me — I must be OK! (Hoover, 1980, p. 28).

Sick/well self-concept is of particular interest and importance in diabetics since the nature and course of diabetes affects individuals in unique ways to influence their adaptations in perceiving themselves as sick or well. The unpredictability of the course can itself be a major stressor for some individuals (Rodin, 1983). There are diabetics whose disease is relatively asymptomatic. Having diabetes without experiencing symptoms or having a progressive course can pose problems for the diabetic's perception of himself. For him enactment of the sick role (Parsons, 1958) is frequently ambiguous and can fluctuate over time. Sakalys (1971) describes the frequent "marginal" role in which people with progressive illnesses are prone to view themselves and be viewed by others — neither really sick nor really well. An individual with diabetes can, therefore, have a diffuse or conflicted self-concept relative to sickness and wellness.

Cognitive-Affective Nature

Perception of symptoms. Initially, people with diabetes may be asymptomatic or have vague and insidious symptoms. Diabetes is frequently diagnosed when individuals are asymptomatic. In one study (McDonough, 1981) forty-two per cent of the diabetic sample were in this group. One month after diagnosis these diabetics said that they "felt no different now" (p. 48) than they did before their diagnosis. This lack of symptoms and the expressed feeling of these diabetics makes it logical that such people may have the initial disbelief and denial of their disease process that is characteristic of early reactions to any chronic illness.

Observations of the author concur with Rodin's (1983) point that the lack of visibility of their disease deters some diabetics from coming to terms with their perception of themselves. They can avoid initiating any discussion about diabetes with their family and friends, frequently retaining conflict about themselves.

Complications of diabetes as well may not be perceived for many years. One diabetic told the author, in a tone of resignation, that when he first had diabetes if he did the right things he was "fine." Now that he had renal complications, he felt terrible no matter what he did right. It is understandable that this man would relate his constant fatigue now to being sick since he previously viewed himself as generally well despite years of unseen and unfelt progressive nephrosclerosis. Although that active but covert behaviour of metabolic processes and possible structural alterations are present, individuals may not consider themselves sick if these processes do not result in experienced symptoms. For between the abnormal biochemical processes which are felt and those which are not is the threshold of consciousness. Awareness makes what may objectively be a continuum of pathology subjectively into things of two very different orders.

Cognitive structure. One extremely important factor in how individuals perceive themselves as sick or as well is their pre-existing cognitive structure. Ausubel (1967) describes how a person relates new ideas to his cognitive structure:

It is . . . necessary . . . to relate the new . . . to relevant established ideas in his own cognitive structure; to apprehend in what ways it is similar to and different from related concepts and propositions; to translate it into the frame of reference of his own experience and vocabulary; much reorganization of his existing knowledge (p. 11).

Individuals vary in the rigidity of their mental categories. This ranges from thinking in very dichotomous categories to making complex combinations among categories (Joyce & Weil, 1972, pp. 300-302). Some diabetics are able to mix their conceptual categories, making distinctions as to which characteristics of being sick they feel apply to them. For example, they make a full incorporation of even unfelt abnormalities of their metabolism into their conception of sick, but are clear that they retain characteristics of wellness in being relatively free of felt symptoms and carrying out their usual role functions. They then move along a sick-well continuum as symptoms or incapacities appear and abate.

Diabetics who are more categorical thinkers are prone to feel confusion and a diffuse self-concept as to whether they are sick or well if they mix these categories. Some can adapt their self-concept better if a new category is formed. They may form, or be assisted in fostering, a new category which retains some elements of being well and not others; some elements of being sick and not others. This way of adapting concepts is not uncommon in other areas of life, for example, what can be thought of as a mixture can also be conceptualized as a distinct entity, a hybrid. To some types of categorical thinkers this sort of adaptation to a positive category may be reassuring.

Similar is the concept of chronic illness, where the idea of self-management is coming more to the fore. Given time, and perhaps a destigmatized terminology, a distinct identity may evolve in our culture, and therefore more readily in individuals' conceptual thinking. This new category is not yet culturally well developed however. At the present time, for other types of categorical thinkers, it can be helpful to retain intact sick and well concepts with the distinction made in the concept "disease" or "condition." They can conceptualize their diabetes on one level, that of an underlying biochemical disease, and view themselves as sick or well at different points of time depending on criteria such as subjective symptoms or role functioning.

Attitudes. No matter how people are *able* to integrate their diabetes into their cognitive structure, their attitudes about being sick or being well greatly influence *how* they integrate it. For some diabetics just knowing there is something abnormal in their metabolism or knowing that complications are possible is very threatening, inclining their self-perception toward sickness. This may be displayed in excessive anxiety for the current context of their situation. When the deviation from normal health is threatening and denial is operative, some diabetics totally perceive of themselves as well. They are not really able to relate their biochemical disorder to themselves in any way.

Attitude makes a significant difference in whether a person experiences psychological marginality. Mann (1959) suggested that a marginal social situation may only amplify certain features of some individuals' personalities which already exist. For instance, with people on the border between two cultures, the arena in which the term "marginal" was originally used, it has been found that what some people feel as conflict and diffuseness, others can view as positive. If a person can make a change in attitude from negative to positive, an existential shift occurs. The shift is from psychological marginality to possibly seeing oneself as an "intermediary" (Stonequist, 1937, p. 178), a person who can relate to both cultures, see each with increased objectivity, and help others bridge the two cultures. Similarly, many well-adjusted diabetics who can relate both to a state of sickness and of wellness seem to view themselves implicitly as intermediaries who can help others bridge the two states. They feel that they have special insight to contribute in helping other diabetics with problems and also bringing practicality and realism to health care workers who plan diabetic management.

Life Process

Stage of life. In the diabetic's adaptations of his self-concept as sick or well, the degree to which a stable identity has already been formed will be influential (Bruhn, 1977). The stage of development in adulthood is also important in how the individual will integrate diabetes into his self-concept.

In young adulthood the establishment of autonomy is very important. Diabetes can be especially crucial at this time in terms of establishing a family and an occupation. If diabetes causes problems in these areas, or if the young adult has always thought of himself as well, developing diabetes or having to consider it in life choices can cause individuals to experience a great feeling of deviation in terms of their self-concept. One young adult who developed diabetes is vivid in the author's mind. Even a year after his diagnosis he vacillated between excessive fears of complications and excessive denial of his diabetes, with repeated hospitalizations after drinking with his peers.

In older age groups, individuals already may have had some experience with chronic illnesses. Diabetes may not have as dramatic an impact if they have already begun to integrate some aspects of illness into their self-concept; on the other hand, life patterns are more established and thus more difficult to alter to include self-management activities such as an ordered meal plan. Complications of diabetes can also interrupt the actualization of career achievements and retirement plans after many years of sacrifice and careful planning. These factors can heighten the perception of being sick.

Lifestyle. Individuals' lifestyles will to varying degrees accommodate the daily management needs of diabetes. For some people such activities are not living the "normal" life indicated by health care personnel and diabetic literature.

The more incongruent individuals' pre-existing lifestyles are with that advised for diabetics, the more likely they seem to perceive of themselves as sick or to go the opposite extreme and completely deny that they need to do anything different.

Jackson (1981) states that diabetics develop the qualities of "planning, discipline and perseverance" (p. 31). For individuals whose lifestyles are already fairly well regulated this may not be difficult. For others with lifestyles at variance with these qualities, the self-management regime can be just "endless routine" (McDonough, 1981, p. 94). This situation again promotes extremes in self-perceptions of illness or health.

Self-management activities. The self-management activities in diabetes embody certain elements of those dimensions of wellness and illness listed in Figure 1. The autonomy and independent achievement characteristic of wellness is becoming increasingly possible with wider use of home blood glucose monitoring (Rodin, 1983) and, for many of these diabetics, self-adjustment of insulin to achieve a narrow range of blood glucose levels. Even the more common self-testing of urine and modification of food intake according to activity level relies on autonomy.

The focus of these activities, however, is on something very different from that of the person with intact physiological processes. These activities also provide "windows" to see deviations in physiological processes that are usually unconscious. The self-management activities are therefore behaviours which provide concrete mechanisms for persons with diabetes to combine conceptually some aspects of being well with some aspects of illness. Thus they may be potentially strong integrative activities toward a sense of wholeness.

This is not true for everyone. For those individuals who are using excessive denial these activities can seem incongruous to their self-conception. Urine testing may be just "a pain in the neck" as one diabetic in McDonough's (1981, p. 70) study said. In early stages of treatment performing activities such as urine testing may just seem incongruous relative to health. "In the real world, it is a completely unacceptable activity — urine is disgusting . . . You are asking (the layman) to do something he has probably considered a 'no-no' since the age of two" (Hoover, 1980, p. 32).

The injection of insulin can have a large impact on the self-concept. The author has observed that, in some people, receiving insulin is highly symbolic of being sick. One highly educated man indicated that giving himself insulin was a reminder of his perceived dependency.

Reciprocal Interaction

It is well known that an individual's perception of being sick or well is to a large extent influenced by his cultural learning about these states (Ahmed et al., 1979; Fabrega, 1979). The individual's perception is constantly modified by how others, especially family members, respond to his behaviour (Benoliel, 1970; Strauss & Glaser, 1975). One young adult in the author's experience was greatly influenced by his parents in viewing himself as quite sick at diagnosis of his diabetes. One of his uncles was diabetic, controlled by oral hypoglycemics. This young man's being treated with insulin made the family greatly exaggerate the contrast with his uncle. This perception encouraged the young man to become focused on the hope of "getting off insulin," when a dramatic change would occur in how sick he would perceive himself to be.

IMPLICATIONS FOR NURSING INTERACTIONS

Through reciprocal interaction nurses, as well as other health care workers, can influence the self-concept of diabetic individuals in terms of sickness or wellness. With reference to the various dimensions of being well and being sick in the chart of Figure 1, there are some dimensions of health which the nurse can modify more effectively than others. For example, a nurse is limited in the ability to modify directly the diabetic's structural organization. The most basic aims of the nurse would seem to be to promote a feeling of well-being and a sense of unity in the diabetic's self-concept. These aims are often achieved by interventions in other dimensions of health, such as providing opportunities for achievement.

In assessing a diabetic's sense of unity, the contextual and personal factors cited in this paper can be used to help identify persons at particular risk for a lack of integration. Cognitive restructuring is especially necessary when the diabetic is becoming aware of his diagnosis and at the onset of complications. Personal characteristics such as "black and white" thinking, a great number of losses in terms of life goals and role functioning, or lifestyles incongruent with diabetic management needs indicate persons who may require special assistance in adapting their self-concept.

Influencing adaptation of the diabetic's ideas, and therefore his self-concept, through exploration with him requires the nurse to identify mental associations of autonomy/dependency and achievement/loss and the affect which the diabetic portrays related to specific events. In this way the nurse can gain greater insight into the individual's implicit thinking and judiciously help him gain increased self-awareness. For example, one diabetic who showed pride in his former role as an intermediary with other diabetics, after he developed the complication of renal failure, had no desire at all to become associated with a lay group of people with kidney disease. Through exploration with the nurse he became more aware that other people with renal failure reminded him he was no longer well. He also developed greater insight into his anger at some health care workers. He felt they seemed to forget he was diabetic when his associations with "just having diabetes" were autonomy, achievement, and a sense of well-being.

The nurse can influence the diabetic's ideas about himself through her own acts and by structuring situations. Callahan, Carroll, Revier, Gilhooly and Dunn (1966) identify the need for the relationship of mutual participation between people with chronic illnesses and health team members. Mutual participation, one example of which Hagey and Buller (1983) describe, promotes the characteristic of autonomy as an aspect of wellness.

The relationship of mutual participation can be used to make the diabetic's lifestyle more congruent with that which he desires. This relationship implies not only joint planning of self-management activities, it also implies a keen awareness on the nurse's part of which aspects of the diabetic's self-management are most crucial, accompanied by a flexible, creative approach toward achieving ultimate objectives. For example, for many diabetics frequent urine testing, though desirable, is not critical.

The nurse can identify particular needs for autonomy in certain diabetics and maximize opportunities for keeping the person informed, e.g., about current blood sugar levels. She can also explore whether more autonomous self-management activities are desired and possible.

In helping the diabetic achieve a greater sense of unity despite a rapid fluctuation in health status, the nurse can call attention to possible markers of sickness and wellness to assist in making transitions of these states more concrete. Accompanying one's activities with explicit comments related to a transition in level of health can be done when removing an intravenous needle or cutting a patient armband on discharge from the hospital.

Situations can be fostered in which diabetics with conflict about themselves can interact with diabetics who provide positive examples of adaptation and integration of their self-concept. Participation in activities of the Canadian Diabetic Association, or just receiving its lay-oriented news magazine, *Diabetes Dialogue*, gives the individual with diabetes a new reference group with which to identify. This contact can assist, via symbolic interaction, in coming to terms with a self-concept having some of the characteristics of health and some of illness.

CONCLUSION

Many factors influence adaptations of the diabetic's self-concept in terms of being sick or being well, there being great variety among individuals in how they perceive themselves. The nurse's concerns need to be that she understand each person's perceptions and their implications and that she strive to promote the individual's sense of unity and well-being.

REFERENCES

- Ahmed, P. I., Kolker, A., & Coelho, G. V. Toward a new definition of health: An overview. In P. I. Ahmed & G. V. Coelho (Eds.), *Toward a new definition of health: Psychological dimensions*. New York: Plenum, 1979.
- Arpin, K., & Parker, N. Developing a conceptual framework. *Nursing Papers*, 1976, 7(4), 28-34.
- Ausubel, D. P. *Learning theory and classroom practice*. Toronto: Ontario Institute for Studies in Education, 1967.
- Bateson, G. *Mind and nature: A necessary unity*. London: Wilwood House, 1979.
- Benoliel, J. Q. The developing diabetic identity: A study of family influence. *Communicating Nursing Research*, 1970, 3, 14-32.
- Bruhn, J. G. Self-concept and the control of diabetes. *American Family Physician*, 1977, 15(3), 93-97.
- Callahan, E. M., Carroll, S., Revier, Sister P., Gilhooly, E., & Dunn, D. The "sick role" in chronic illness: Some reactions. *Journal of Chronic Disease*, 1966, 19, 883-897.
- Fabrega, H. Jr. Disease and illness from a biocultural standpoint. In P. I. Ahmed & G. V. Coelho (Eds.), *Toward a new definition of health: Psychosocial dimensions*. New York: Plenum, 1979.
- Hagey, R., & Buller, E. Drumming and dancing: A new rhythm in nursing care. *The Canadian Nurse*, 1983, 79(4), 28-31.
- Hoover, J. Another point of view. In B. A. Hamburg, L. Lipsett, G. E. Inoff & A. L. Drash (Eds.), *Behavioral and psychosocial issues in diabetes: Proceedings of the national conference*. Washington: U.S. Department of Health and Human Services, 1980.

- Jackson, C. Diabetes: How your patient looks at it. *Nursing*, 1981, 11(5), 30-31.
- Joyce, B., & Weil, M. *Models of Teaching*. Englewood Cliffs, N.J.: Prentice-Hall, 1972.
- Mann, J. W. Group relations and the marginal personality. *Human Relations*, 1959, 11(1), 77-91.
- McDonough, B. *The impact of information and decision-making on the compliance and adaptation of newly diagnosed insulin dependent diabetics*. Unpublished Master's thesis, Department of Community Health, University of Toronto, 1981.
- Moos, R., & Tsu, V. D. The crisis of physical illness: An overview. In R. Moos (Ed.), *Coping with physical illness*. New York: Plenum, 1977.
- Parsons, T. Definitions of health and illness in light of American values and social structure. In E. G. Jaco (Ed.), *Patients, physicians and illness*. Glencoe, Ill.: The Free Press, 1958.
- Rodin, G. M. Psychosocial aspects of diabetes mellitus. *Canadian Journal of Psychiatry*, 1983, 28, 219-223.
- Sakalys, J. Stages of adaptation to illness and disability: A psychosocial view. In M. Duffey et al. (Eds.), *Current concepts in clinical nursing*. St. Louis: Mosby, 1971.
- Smith, J. A. *The idea of health*. Unpublished doctoral dissertation, New York University, 1979. As cited in Fontes, H. M. An exploration of the relationships between cognitive style, interpersonal needs, and the eudaimonistic model of health. *Nursing Research*, 1983, 32, 92-96.
- Stonequist, E. *The marginal man*. New York: Charles Scribner's Son, 1937.
- Strauss, A. L., & Glaser, B. *Chronic illness and the quality of life*. St. Louis: Mosby, 1975.
- University of Toronto Faculty of Nursing. A conceptual framework for nursing, unpublished manuscript, 1981.

RÉSUMÉ

L'adaptation au concept de soi des adultes atteints de diabète

De nombreux facteurs influent sur l'idée qu'un diabétique se fait de lui-même en tant qu'être malade ou bien portant. La perception des symptômes, la structure cognitive, les attitudes, l'étape de la vie, le mode de vie, l'autonomie et les relations avec autrui constituent certains facteurs que cet article aborde dans le cadre conceptuel de sciences infirmières élaboré à l'université de Toronto (1981). L'article identifie diverses dimensions de la santé et de la maladie; l'infirmière doit comprendre les perceptions de chaque malade, et les conséquences possibles de ses perceptions. Elle doit l'encourager de façon à favoriser chez lui un sens d'unité et de bien-être.

FACTORS INFLUENCING DIETARY ADHERENCE AS PERCEIVED BY PATIENTS ON LONG-TERM INTERMITTENT PERITONEAL DIALYSIS

Margaret R. Hume

One of the many adaptive tasks of the individual with a chronic illness is the management of a medical regimen. Nonadherence to prescribed health regimens is a familiar problem to health professionals. The complex and demanding regimen of the person with end-stage renal disease (ESRD) usually includes dietary modifications designed to supplement dialysis in alleviating the physiological imbalance of impaired kidney function. While some patients on home dialysis programs may require little dietary restriction, those on intermittent hospital schedules usually have a prescribed intake of protein, sodium, potassium and fluid. Studies on dietary adherence in dialysis populations (Blackburn, 1977; DeNour & Czaczkes, 1972; Hartman & Becker, 1978; Procci, 1978) indicate that nonadherence is a significant problem.

The ongoing contact between patients on hospital maintenance dialysis programs and the dialysis team provides team members with the opportunity to assist these patients in making the required behavioural changes. Although adaptation to hemodialysis has been studied extensively, there is still little reliable information on the factors influencing dietary adherence in dialysis patients, especially those on peritoneal dialysis programs. Such information would assist nurses and other health workers in planning appropriate interventions.

PURPOSE AND OBJECTIVES

Assuming that individuals are able, to some extent, to recognize factors influencing their behaviours, the purpose of this study was to identify those factors perceived by patients on long-term intermittent peritoneal dialysis as influencing adherence to their prescribed diets. The objectives of the study were:

1. To describe the perceptions of patients on long-term intermittent peritoneal dialysis of the influence on their dietary behaviour of selected health values, health beliefs and situational factors.

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2. To identify those health values, health beliefs and situational factors perceived most frequently as having a positive or a negative influence on dietary adherence.

3. To examine the perceived influence of these health values, health beliefs and situational factors in relation to self-assessments of dietary adherence.

LITERATURE REVIEW

Patient compliance with medical regimens has been studied extensively especially in relation to prescribed medications. Reported findings of factors associated with compliance vary considerably. Surveys of studies (Haynes, 1976; Marston, 1970; Schmidt, 1977) indicate that sociodemographic factors and knowledge of illness or therapy are not often related to compliant behaviour. Compliance appears to be correlated more strongly with the perceived severity of the illness, the duration and complexity of the regimen, family support and some aspects of the doctor-patient relationship.

Studies investigating the factors influencing dietary adherence in hemodialysis patients have produced findings quite similar to those of compliance studies in general. Blackburn (1977), Cummings, Becker, Kirscht and Levin (1982) and Hartman and Becker (1978) reported no association between knowledge of the regimen and dietary adherence. A few inconsistent relationships have been found between specific demographic factors and specific aspects of the prescribed diet (Blackburn, 1977; Hartman & Becker, 1978; O'Brien, 1980). Hartman and Becker (1978) and O'Brien (1980) reported increasing dietary compliance over time while Blackburn (1977) and Cummings et al. (1982) reported negative associations between dietary compliance and duration of the regimen. Although family support has generally appeared to have a positive influence on dietary behaviour (Hartman & Becker, 1978; O'Brien, 1980; Procci, 1978), Cummings et al. found no relationship between dietary adherence measures and family support.

DeNour and Czaczkes (1972), studying the effects of a number of personality factors on dietary compliance in hemodialysis patients, reported that a low frustration tolerance and gains from the sick role were the factors most frequently associated with noncompliance, a finding reported also by Hartman and Becker (1978). No association was found between compliance and denial. Similarly, Yanagida, Streltzer and Siemsen (1981) found no association between denial and compliance with fluid restriction.

Hartman and Becker (1978) evaluated the relationship between specific health beliefs and dietary-medication noncompliance. The findings suggested that the less compliant patient was less concerned about his kidney condition and the possible effects of nonadherence. He also exhibited less faith in all aspects of the regimen and perceived many barriers. In a later study Cummings et al. (1982) found that the same health belief variables were related more closely to the subjects' self-reports of adherence than to objective measures. As suggested by Hartman and Becker (1982), the use of health beliefs and attitudes as study variables seems to be one of the more promising approaches to compliance research. These factors, if associated with adherence, may be amenable to change through interventions of the health team.

THEORETICAL FRAMEWORK

The study was based on a dietary adherence model (Figure 1) developed by the investigator utilizing Becker and Maiman's (1975) modification of the Health Belief Model. The Health Belief Model (HBM), a set of health belief variables, was developed to predict preventive health behaviours. In the HBM, the likelihood of taking a recommended preventive health action results from the perceived threat of the disease in question and the perceived benefits and barriers to the preventive action (Rosenstock, 1974).

Retaining the underlying theory of the original formulation, Becker and Maiman (1975) proposed a model for the study of compliance with prescribed health regimens. The readiness to take a prescribed health action is explained as the product of a general motivation toward health, the perceived threat of the illness, the value of reducing that threat, the expected outcomes of the proposed health action and the perceived barriers to taking the proposed action. The state of readiness interacts with modifying variables, determined largely from compliance studies, to determine the likelihood of compliance.

In the dietary adherence model developed for the present study, the investigator included those elements of the Becker-Maiman Model which seemed most applicable to the study problem. Factors considered in the selection and modification of variables for the new model were the long-term nature of the illness and the regimen, the interaction of the study population with different categories of health workers and the feasibility of researching the variables from a patient perspective. Category headings were altered to be more descriptive of the modified variables.

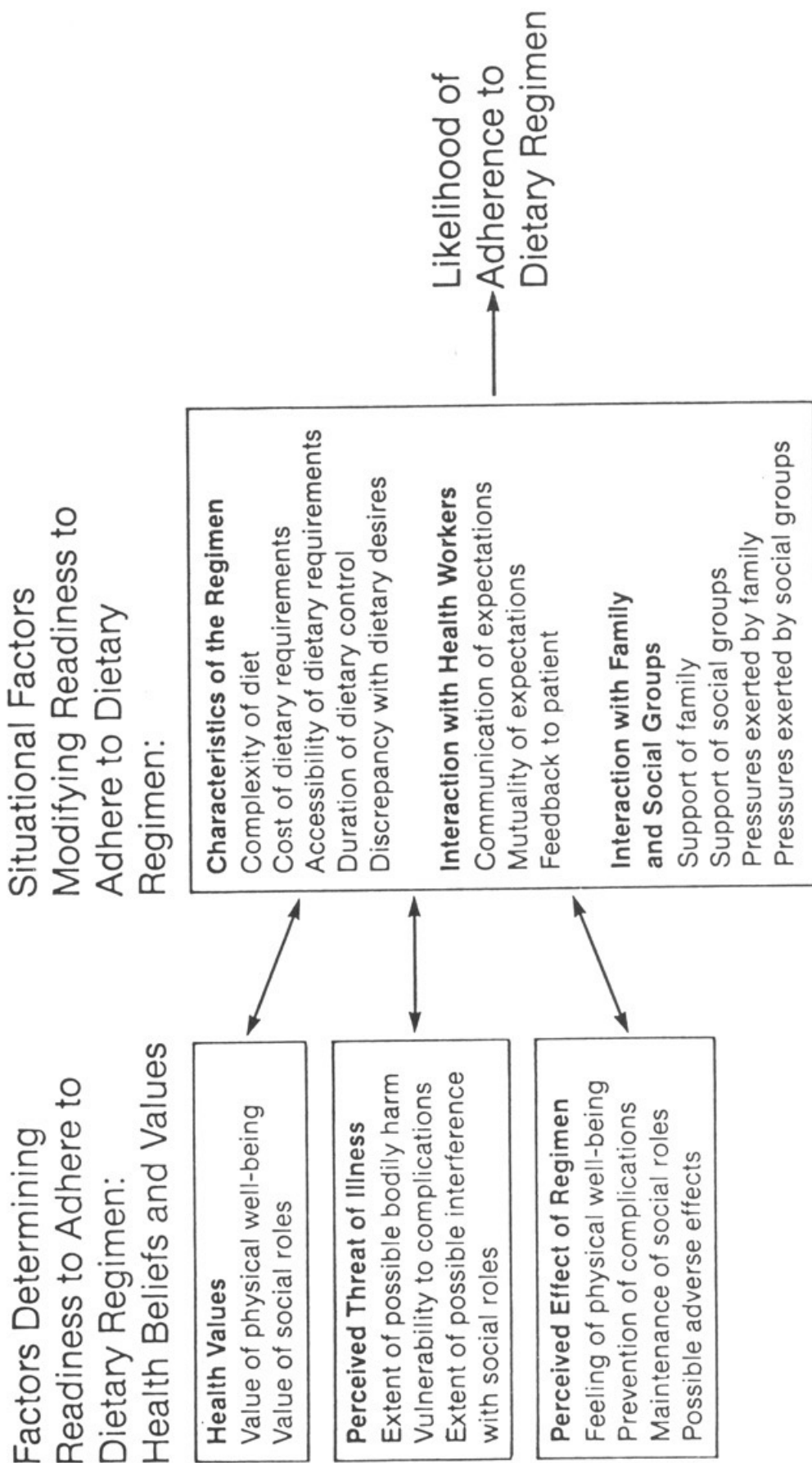


Figure 1. Dietary adherence model.

In the dietary adherence model, readiness to adhere to the prescribed dietary regimen is depicted as resulting from the value placed on health, the perceived threat of illness (ESRD) and the belief that following the diet could reduce that threat. Situational factors modifying readiness include characteristics of the dietary regimen and the interactions of the patient with health workers, family and social groups.

OPERATIONAL DEFINITIONS

Prescribed dietary regimen: The recommendations of a physician or other health worker concerning the types and/or amounts of food and fluid to be consumed.

Dietary adherence: Food and fluid consumption according to the recommendations and instructions of a physician or other health worker. In this study the terms adherence and compliance are used interchangeably.

Positive influence on dietary adherence: A force which increases the probability of an individual adhering to a prescribed dietary regimen.

Negative influence on dietary adherence: A force which decreases the probability of an individual adhering to a prescribed dietary regimen.

Health beliefs: An individual's estimate of (a) his present health, (b) the probable effects of an illness (renal failure) on his present and future health, and (c) the probable effects of a health behaviour (dietary adherence) on his present and future health.

Health values: An individual's estimate of (a) the worth of maintaining a certain level of health, (b) the relative worth of physical well-being and social roles, and (c) the worth of the expected outcomes of a health behaviour (dietary adherence).

Situational factors: The forces, other than the health beliefs and values of an individual, which influence a health behaviour (dietary adherence). The selected situational factors for this study are the characteristics of the dietary regimen, interactions with health workers and interactions with family and social groups.

METHODOLOGY

The Sample

A convenience sample of 25 subjects from five dialysis units was selected. Ages of the subjects ranged from 29 to 79 years, with an

average age of 51 years. A majority of the subjects (15) were male, and a majority (15) were married. All of the subjects could speak and understand English. The investigator was not involved in the care of any of the subjects.

The length of time on peritoneal dialysis ranged from three months to four years with most subjects on 20-hour hospital dialysis periods twice weekly. All subjects had prescribed dietary modifications, with seven subjects requiring diabetic as well as renal diets. Selected subjects had no known infection and had not been hospitalized other than for dialysis in the four weeks preceding data collection.

Instrument

Data were obtained using a semi-structured interview developed by the investigator. The format followed the dietary adherence model, including items related to health beliefs and values, the factors determining readiness, and the selected situational factors modifying readiness. The items were paired, questioning first the subjects' perceptions of the relative presence or absence of the suggested factor followed by their perceptions of the influence of that factor on dietary adherence. For both items, subjects selected a response from a three-point scale. In some categories there were additional questions which further qualified the responses. Two final open-ended questions allowed subjects to suggest possible influencing factors not included in the structured items.

Demographic data (age, marital status) were obtained from the subjects, and information on illness history, recent predialysis blood chemistry and interdialysis weight gain were obtained from the medical record. Subjects were requested to rate their dietary adherence during the past month as "good," "adequate" or "poor" using their own perceptions of these terms and were asked to describe their prescribed diets.

The instrument was examined for content validity by a clinical nurse specialist and a renal head nurse and was pretested on four patients in one of the study units.

Procedure

Permission to conduct the study was obtained from the hospitals and attending physicians. All eligible patients, approached initially by the head nurse and then by the investigator, agreed to participate. Subjects signed a consent form explaining the purpose and nature of the study and the measures to ensure confidentiality. The investigator

conducted all interviews during a dialysis period in hospital to avoid intrusion into the subject's limited time at home. Medical data were obtained from hospital records either preceding or following the interview.

DATA ANALYSIS

The data were analyzed by descriptive statistics only using frequency distributions, cross tabulations and category percentage scores (percentage of factors in each category perceived as having a positive, negative or no influence on dietary adherence). Content analysis was done on the responses to the open-ended items and on any additional comments.

For the analysis of the subjects' perceptions of the presence or absence of a suggested factor, the two highest rankings on a three-point scale, e.g. "considerably," "somewhat," were considered as presence, while the lowest ranking, e.g. "very little if any," was considered as absence. In analyzing the perceived influence on adherence, the identification of a factor as encouraging adherence was considered a positive influence. Factors reported as discouraging adherence were classified as negative influences. The data did not reveal the perceived degree of influence on adherence.

Using criteria considered as acceptable by all of the study units, dietary adherence was rated "good," "adequate" or "poor" according to blood chemistry and weight gain measures. Since the study focused on patients' perceptions, the objective ratings of adherence were used only for comparison with the subjects' self-assessments.

The investigator and a renal dietitian classified knowledge of the diet as "adequate" or "inadequate" according to the subjects' descriptions of their diet instructions. The ratings were based on an overall judgement of knowledge with an inter-rater reliability of 92%. Knowledge ratings were used only to determine the extent to which the subjects' interpretations of "diet," as used in the interview questions, was congruent with the actual dietary prescriptions.

FINDINGS

Assessments of Adherence and Knowledge

Predialysis blood chemistry levels and interdialysis weight gain, along with self-reports of adherence, suggested that the majority of

subjects had adhered reasonably well to their prescribed diets during a three to four week period immediately preceding data collection. Acknowledging the arbitrary nature of any adherence criteria, a majority of subjects (20) received a rating of "good" for both serum potassium and blood urea nitrogen (BUN) levels. The ratings for weight gains, indicating fluid intake, were divided almost equally among "good," "adequate" and "poor." In the self-reports, 7 subjects rated their overall adherence as "very good," 12 as "fairly good" and 6 as "poor." Comparisons of the self-ratings with the clinical measures suggested that most subjects were able to estimate their recent dietary behaviour with reasonable accuracy.

Most subjects were on high (80 gm.) protein diet to compensate for protein loss during dialysis. Several subjects referred to difficulty eating sufficient meat. The BUN levels were used to reveal excess protein intake only and did not provide information on the adequacy of the protein intake.

The dietary knowledge of 19 subjects was considered "adequate." Most of the 6 subjects whose knowledge was considered "inadequate" made inaccurate statements related to either protein or sodium. Possibly these aspects of the diet are not emphasized as much as fluid and potassium because of the more immediate dangers associated with fluid retention or high serum potassium levels. Knowledge was assessed by verbal recall only. At home, the subjects or family members may have used printed guidelines for food preparation.

Factors Influencing Dietary Adherence

The subjects reported more positive than negative influences on dietary adherence. Of the total responses to items questioning the perceived influence of suggested factors, 39% indicated a positive influence on adherence while only 17% indicated a negative influence. Health beliefs and values accounted for most of the positive forces while situational factors, especially those related to the regimen itself, were mentioned most frequently as barriers to adherence. The factors identified most frequently as having positive and negative influences on dietary adherence are listed in Tables 1 and 2 respectively. Although 44% of the responses indicated that the suggested influences had no direct effect on adherence, additional comments offered by subjects suggested that some of these factors were sources of stress. Influencing factors are discussed further under the categories of the dietary adherence model.

Table 1
Factors Most Frequently Perceived as Having
a Positive Influence on Dietary Adherence

Perceived factor	Number of subjects responding
Importance of diet to health (physical)	23
Value of health (physical)	23
Dialysis team's communication of importance of diet	20
Severity of illness	19
Family's efforts to help	18
Duration of dietary regimen	14
Symptoms from dietary nonadherence	13
Importance of diet in maintaining activities	13
Value of maintaining activities	12
Presence of good appetite	11

N = 25

Table 2
Factors Most Frequently Perceived as Having
a Negative Influence on Dietary Adherence

Perceived factor	Number of subjects responding
Change from previous dietary habits	15
Uncomfortable thirst	12
Overall difficulty of diet	11
Poor appetite	8
Difficulty understanding instructions	7
Increase in time and effort for preparation of food	6
Lack of discussion of weight and blood tests	6
Difficulties caused by family	5
Interference with activities by dietary restrictions	4
Lack of knowledge of long-term effects of nonadherence	4

N = 25

Health beliefs and values. The health values considered included the subjective value of physical well-being and the value placed on maintaining social roles. In the study questions social roles were examined by referring to "normal activities." Most subjects perceived physical well-being as "very important" and normal activities as "fairly important." Some subjects added comments that the illness and dialysis had interfered to such an extent with normal activities that these activities had lost the importance that they once had. Almost all (23) subjects stated that the value that they held for physical health had a positive influence on dietary adherence, while about one-half of the sample (12) reported that the value of maintaining social roles encouraged adherence.

The selected factors representing the threat of illness were the perceived severity of illness, concern over further health problem and the interference of the illness with social roles. Almost all of the subjects perceived the illness as serious and as having disrupted social roles, while fewer than one-half of the subjects expressed concern about further health problems.

In agreement with literature reviews (Haynes, 1976; Marston, 1970) that have indicated that the patient's perception of the severity of an illness influences compliance, most (19) subjects reported that the seriousness of ESRD encouraged them to try to stay on the diet. The threat did not seem to have reached an inhibiting level since only one subject stated that knowing that the illness was very serious discouraged dietary adherence. Since "serious" was not defined, responses in this section do not indicate if the subjects were considering the irreversibility of ESRD or only the immediate threat.

In keeping with the findings related to health values and threat of illness, subjects also related the effects of the regimen more to present physical well-being than to future health or maintaining normal activities. Almost all subjects stated that the main motivational factor in their dietary adherence was the belief that the diet was important to physical health. Less than half (12) of the sample expressed the belief that following the diet could help them to maintain normal activities and only seven stated that concern over possible long-term effects of nonadherence was an influencing factor.

Approximately one-half (13) of the subjects thought that they had experienced symptoms due to nonadherence, while 12 of these reported that these symptoms probably led to closer adherence at least for a short period of time. The symptoms perceived most frequently as resulting from dietary indiscretion were shortness of breath, edema, chest pain and muscles cramps. A few patients commented that too much potassium could be dangerous even though they might have no symptoms.

Overall, maintaining social roles and long-term health appeared to be less influential factors in dietary adherence than present and short-term physical health. The disbelief that the diet could have much effect on the maintenance of many activities may have been realistic for some subjects, such as those with diabetes who perceived loss of vision as their main obstacle. Secondary gains from the sick role could also have determined the extent to which the desire to resume social roles influenced dietary adherence. This factor was not examined in this study, but previously mentioned research (DeNour & Czaczkes, 1972; Hartman & Becker, 1978) found significant associations between dietary noncompliance and secondary gains from the sick role.

The apparent lack of concern or belief of some patients concerning further health problems and long-term effects of dietary abuse may have been related to lack of knowledge or to denial of possible further problems. Denial has been shown to be an extensively used defence mechanism among dialysis patients (Short & Wilson, 1969; Yanagida, 1981). When present, belief in the susceptibility to further health problems was usually perceived as motivating dietary adherence.

Situational factors. Situational factors considered included those related directly to the dietary regimen and the interactions of the subjects with health workers, family and social groups. While situational factors accounted for most of the perceived barriers to dietary adherence, a few factors such as duration of the regimen, family support and some interactions with the health team appeared to support adherence.

The extent of required behavioural change has frequently been associated with the level of compliance to prescribed regimens (Haynes, 1976). In the present study, change from the previous dietary pattern was the factor reported most frequently (19 subjects) as interfering with dietary adherence. Although many subjects had similar dietary prescriptions, the perceived degree of required change varied considerably. Change in dietary pattern might be anticipated as a major barrier to dietary adaptation in this patient group because of the number of changes required in both one cluster of behaviours, the diet, and in other behaviour clusters related to other aspects of the patient's life style (Byrne & Thompson, 1978).

Thirst is well documented as a common problem among dialysis patients. In this study 21 subjects reported uncomfortable thirst, with 12 indicating that thirst caused them to exceed the recommended daily fluid intake. Others noted that although they stayed within the fluid allowance, thirst was often distressing. Subjects showed limited awareness of possible thirst-relieving measures.

Contrary to the reports of compliance research surveys (Haynes, 1976; Marston, 1970) more subjects (14) thought that their dietary adherences had increased rather than decreased (3 subjects) over time. The three subjects who reported a decrease in adherence and nine of those who perceived improved adherence had been on dialysis more than one year. As previously noted in the literature review, studies on hemodialysis groups have produced differing findings on the relationship of duration of the regimen and compliance. Comments offered by subjects suggested that it takes time to become familiar with the diet and realize its importance. Hartman and Becker (1978) further suggest that those patients who are better compliers may survive longer, producing the apparent positive relationship between adherence and duration of the regimen.

Using their own interpretation of the term "difficult," less than half of the sample (11) stated that the diet was very difficult to follow except during the first couple of months. Less than one-third (7) indicated that difficulty understanding instructions probably led to nonadherence. Although only a few subjects reported that cost of food and factors related to food purchase and preparation actually contributed to nonadherence, others commented that these factors were problems.

The reported influence on dietary adherence of the interactions between subjects and the dialysis team varied considerably for the different forms of interaction. All subjects perceived that some member of the health team had communicated the belief that the diet was an important aspect of care, and 20 subjects stated that this communication encouraged adherence. A majority (17) of subjects reported that they thought they and the dialysis team shared similar expectations about how closely they should follow the diet. A few subjects referred to frustration due to differing expectations of team members. O'Brien (1980) found a significant relationship between treatment compliance in hemodialysis patients and their perceptions of the expectations of the health team. In the present study only 10 patients stated that mutuality of expectations probably motivated adherence.

Less than one-half of the subjects perceived that the dialysis team usually discussed weight changes and blood tests with them or expressed approval for apparent dietary adherence, but most of the subjects who stated that these interactions had occurred, reported that they encouraged adherence. In contrast, only one of the ten subjects who reported receiving comments of disapproval for nonadherence stated that disapproval prompted better dietary behaviour. These findings suggest that praise and information-giving are more useful motivational strategies than rebuke.

Although nurses have more contact with hospital dialysis patients than other team members, many subjects viewed nurses as having little or no involvement with diet therapy. Little mention was made of interactions with nurses, and in response to an open-ended question asking what nurses could do to assist with the diet, 11 subjects remarked that nurses had nothing to do with the diet. The rotation of nurses in some of the units may have limited their interventions in relation to diet therapy, and some nurses may not have viewed diet therapy as a part of nursing care.

Interactions with the family appeared to exert considerable influence on dietary adherence in this patient group. Family support, especially that of the spouse, was reported as a positive influence on adherence by a majority (18) of the subjects. Actions mentioned most frequently as helpful were verbal encouragement and the preparation of meals according to dietary orders. Comments made by the unmarried subjects suggested that some problems arose because the person responsible for food preparation, usually a parent or child, did not adequately understand the diet.

Conversely, friends were seen as having very little influence on dietary behaviour, with only four subjects indicating that friends created a positive influence and three subjects noting that friends made it difficult to follow the diet. The apparent lack of influence by friends was probably related to the decrease in social interactions mentioned by several subjects. Also, the complexity of the regimen may have made friends reluctant to become involved with the patient's dietary needs.

Comparison of Self-assessments of Dietary Adherence and Factors Perceived as Influencing Adherence

Subjects who rated their recent dietary adherence as "very good" identified 44% of the suggested factors as positive influences and 12% as negative influences. In the group with "poor" self-ratings, 31% of the responses were positive and 38% were negative. The specific factors most frequently perceived as having positive or negative effects on adherence were quite similar between the two groups with the exception of family support which was reported as positive influence by all of the seven subjects in the "very good" group and only two of the six subjects on the "poor" group.

These findings would seem to support the well accepted opinion of the importance of the family in adaptation to chronic illness. The findings also suggest that dietary adherence in this sample might be a function of numbers of positive or negative forces rather than specific types of forces. While self-reports of adherence have questionable validity (Gordis, 1976), the selection of subjects with self-ratings at either end of a three-point scale may have helped to make the comparison meaningful.

IMPLICATIONS FOR PRACTICE AND RESEARCH

Gaining an understanding of the patient's perceptions of his situation is considered essential if health workers are to assist in adaptation to a long-term illness. The findings of this study cannot be generalized because of the small nonrandomized sample and, especially, the exclusion of non-English speaking patients. However, the data may provide ideas for the examination of practices in any dialysis unit and illustrate the need for further research on dietary adherence from the patient's perspective.

The frequent identification of some factors as being both present and having a positive influence on dietary adherence supports the continued efforts of the health team in these areas. Consistency in the communication of the severity of the illness and importance of the diet provides a realistic basis for the patient to develop his own belief system. Education and support of family members help to direct the important influence of the family. The findings suggested that spouses were being well prepared, but more attention might be required by family members other than the spouse who were responsible for diet preparation. Other factors which were less frequently reported as present, but which, when present, were perceived as positive influences might be emphasized more consistently. Subjects appeared to appreciate recognition for their efforts to follow the diet and discussion and explanation of clinical measures. They may have needed more help in understanding, where realistic, how the diet might indirectly help them to maintain social roles. Some subjects did not appear ready to consider long-term effects, but learning opportunities could be provided for those who demonstrate readiness.

The effects of some factors frequently perceived as interfering with adherence might be lessened somewhat by interventions such as ensuring that dietary patterns are altered no more than necessary to meet each patient's needs and by helping patients find substitutes for favourite foods. Patients could be encouraged to experiment with permitted thirst-relieving measures.

The numbers as well as the types of influencing factors require assessment, especially situational factors perceived as barriers. If many negative influences exist, attempts to reduce the number of negative factors, even apparently minor ones, might increase the likelihood of dietary adherence.

The perceptions of many patients of the lack of involvement of nurses with diet therapy indicate a need for nurses to examine their role in care related to the dietary aspect of the dialysis program. The extensive nurse-patient contact gives nurses a strategic position to collaborate with the dietitian and physician in helping patients cope with this aspect of the total regimen.

For further investigation the present study might be modified to include a larger sample, with translation provided for non-English speaking subjects. A scoring system to allow correlations between measures of dietary adherence and factors perceived as influencing adherence would yield further evidence as to whether the patient's perceptions of influences underlying his behaviour provide useful guidelines for the planning of care.

REFERENCES

- Becker, M. H., & Maiman, L. A. Sociobehavioral determinants of compliance with health and medical care. *Medical Care*, 1975, 13, 10-24.
- Blackburn, S. L. Dietary compliance in chronic hemodialysis patients. *Journal of the American Dietetic Association*, 1977, 70, 31-37.
- Byrne, M. L., & Thompson, L. F. *Key concepts for the study and practice of nursing* (2nd ed.). St. Louis: Mosby, 1978.
- Cummings, K. M., Becker, M., Kirscht, J., & Levin, M. Psychosocial factors affecting adherence to medical regimens in a group of hemodialysis patients. *Medical Care*, 1982, 20, 567-580.
- DeNour, A. K., & Czaczkes, J. W. Personality factors in chronic hemodialysis patients causing noncompliance with medical regimen. *Psychosomatic Medicine*, 1972, 34, 333-344.
- Gordis, L. Methodologic issues in the measurement of patient compliance. In D. L. Sackett & R. B. Haynes (Eds.), *Compliance with therapeutic regimens*. Baltimore: Johns Hopkins University Press, 1976.
- Hartman, P., & Becker, M. Noncompliance with prescribed regimen among chronic hemodialysis patients. *Dialysis and Transplantation*, 1978, 7, 978-989.
- Haynes, R. B. A critical review of the determinants of compliance with therapeutic regimens. In D. L. Sackett & R. B. Haynes (Eds.), *Compliance with therapeutic regimens*. Baltimore: The Johns Hopkins University Press, 1976.
- Marston, M. Compliance with medical regimens — a review of the literature. *Nursing Research*, 1970, 19, 312-323.
- O'Brien, M. Hemodialysis regimen compliance and social environment: A panel analysis. *Nursing Research*, 1980, 29, 250-255.
- Procci, W. R. Dietary abuse in maintenance hemodialysis patients. *Psychosomatics*, 1978, 19, 16-24.
- Rosenstock, I. Historical origins of the Health Belief Model. *Health Education Monographs*, 1974, 2, 328-335.
- Schmidt, J. Patient compliance: The effect of the doctor as a therapeutic agent. *The Journal of Family Practice*, 1977, 4, 853-856.
- Short, M. J., & Wilson, W. P. Roles of denial in chronic hemodialysis. *Archives of General Psychiatry*, 1969, 20, 433-437.
- Yanagida, E. H., Streltzer, J., & Siensen, A. Denial in dialysis patients: Relationship to compliance and other variables. *Psychosomatic Medicine*, 1981, 43, 271-280.

RÉSUMÉ

Facteurs influençant l'adhésion à un régime: perceptions des sujets soumis à une dialyse péritonéale intermittente à long terme

Dans le cadre d'une étude descriptive, on a interrogé 25 sujets soumis à une dialyse péritonéale intermittente à long terme quant à l'influence que certaines croyances, certaines valeurs et certains facteurs situationnels peuvent avoir sur l'adhésion à leur régime. Les sujets ont identifié plus d'influences positives que négatives sur leur comportement diététique. Les croyances et les valeurs liées à la santé constituaient la majorité des influences positives, tandis que la plupart des obstacles perçus avaient trait à des facteurs situationnels, notamment les facteurs liés au régime diététique proprement dit. Les sujets qui disaient bien suivre leur régime ont signalé plus d'influences positives et moins d'influences négatives que ceux qui disaient mal suivre leur régime. On a constaté peu de différence entre ces deux groupes quant aux types de facteurs perçus comme ayant des effets positifs ou négatifs. Aucun test d'importance statistique n'a été effectué. Les conclusions suggèrent des domaines où l'intervention de l'équipe de soins est susceptible d'encourager et de faciliter l'adhésion à un régime.

SCHIZOPHRENIA AND THE EFFECT OF PATIENT EDUCATION

Elizabeth A. McCay

Schizophrenia is the most frequent admission diagnosis to a psychiatric facility (Statistics Canada, 1976). Although the diagnosis of schizophrenia does not convey the message of hopelessness that it once did, many problems such as social adjustment and the lack of health promoting behaviours, specifically medication adherence, often preclude the adaptation necessary for improved health (Pyke, 1979; Serban & Thomas, 1974; Van Putten, 1978).

The literature suggests that the individuals' knowledge, attitudes and beliefs pertaining to their illness may be important variables that relate positively to health behaviours (Caplan, Robinson, French, Caldwell, & Shinn, 1976; Given, Given, & Simoni, 1978; Tagliacozzo & Ima, 1970). Beliefs regarding schizophrenia may in fact be inhibiting positive health behaviours as the illness remains in the minds of many a frightening and often unmentionable disease (Lancaster, 1976; Masnik, 1974; Wing, 1978). Educational strategies which have been found to be effective in altering health beliefs, knowledge, attitudes and values about other diseases (Green, 1979), generally are not utilized to dispel the fear of schizophrenia. These strategies have not been validated as effective intervention techniques for psychiatric populations (Blackwell, 1976; del Campo, Carr, & Correa, 1983).

The purpose of this study was to provide baseline data about the effect of patient education on schizophrenic inpatients' health knowledge, beliefs and general health motivation pertaining to their illness.

LITERATURE REVIEW

Although an abundance of literature exists concerning schizophrenia and its treatment, very few studies have focused on patient education for this group (del Campo et al., 1983).

In several studies educational strategies were utilized with different psychiatric populations achieving varied outcomes. Powell, Othmer and Sinkhorn (1977) found that they had good attendance and re-admission rates in three homogeneous aftercare groups in which they taught patients about their illness. In another study, the effect of

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patient education for a group of schizophrenic day care patients resulted in improved measures of self sufficiency and the ability to work for those who completed the program (Jeffries, Note 1). A further positive trend associated with educational interventions was found by Seltzer, Roncari and Garfinkel (1980) in a group of 67 psychiatric inpatients. Results indicated that 9% of the experimental group who received a series of nine lectures about their illness and treatment were noncompliant with medication, while 66% of the control group were noncompliant with medication, after a five month period. The experimental group was also found to be less fearful of addiction to medication and side effects. On the other hand Witt (Note 4) failed to demonstrate improved medication compliance for psychiatric outpatients who received an educational program congruent with their locus of control. Nonetheless, Witt did find that significantly more patients who placed a high value on health complied with medication than patients who placed a low value on health.

Schizophrenic patients health beliefs have not been described extensively in the literature, although some literature concerning attitudes about illness and treatment exists.

Attitudes toward psychiatric illness and treatment have been reported independently and in relation to behaviour. The attitudes of psychiatric patients toward their illness were described by Giovannoni and Ullman (1963) as being comparable to the negative attitudes held by the general public. Specific attitudes toward schizophrenia have been correlated with levels of socially expected activities and lower symptom levels as measured by the Katz Adjustment Scale (Soskis & Bowers, 1969). A positive integrating attitude as opposed to a negative isolating attitude toward schizophrenia relates to increased social activity and decreased symptom levels. Factors contributing to a positive integrating attitude were not specified. Of note is the finding that favourable attitudes toward the treatment and the psychotherapist are associated with good treatment outcomes (Brady, Zeller, & Reznikoff, 1959; Lee, 1979).

In contrast to the aforementioned studies Serban and Thomas (1974) found that positive attitudes toward medication and outpatient care did not correlate with medication compliance or outpatient followup. A recent study by del Campo et al. (1983) reports a similar finding where a positive attitude did not result in the desired response. Specifically, they found that despite the fact that schizophrenic patients acknowledged their illness, they also denied that their readmission to hospital was related to their illness. The authors state that this documented dichotomy is typical of patients with a schizophrenic illness.

Studies concerning educational strategies and health beliefs in other populations demonstrate that health knowledge and beliefs are alterable and may relate positively to health behaviours (Haynes, Taylor, & Sackett, 1979; Marston, 1970). However, further research is required to determine the effect of patient education on health knowledge and beliefs of schizophrenic patients.

CONCEPTUAL FRAMEWORK

The revised Health Belief Model by Becker & Maiman (1975) (Appendix) was selected for use in this study for several reasons: the model's components have been demonstrated to be alterable (Becker, 1974; Mikhail, 1981); some research studies confirm the predictive value of the model in relation to health behaviour (Haynes, 1976; Mikhail, 1981); the model may be applied to various health issues and populations, yet maintains educational and behavioural specificity (Kirscht, 1974). A modified version of the Health Belief Model specifies the specific factors to be considered in this study (see Figure 1). Permission to modify Becker & Maiman's model was not requested since the original intent or meaning was not altered. For the purposes of this study the components of the model were defined as follows:

- Health knowledge: The patient's understanding of the diagnosis, prescribed medication and the ability to recognize early return of symptoms.
- Health belief: What one perceives to be true concerning health. The beliefs consist of:
 1. Perceived resusceptibility: The patient's estimation of the likelihood of having another schizophrenic episode. Also included is the patient's estimation of the accuracy of the diagnosis.
 2. Perceived severity: The patient's estimation of how serious it is to have a schizophrenic illness and what consequences it will have on other aspects of life.
 3. Perceived benefits and barriers: The patient's evaluation of recommended health behaviours including both advantages such as control of symptoms and disadvantages such as side effects.
- General health motivation: The patient's general concern about health matters. Also included are the patient's feelings about doing what the doctor or other health professionals say.
- Modifying factors: Additional factors as specified in Figure 1.

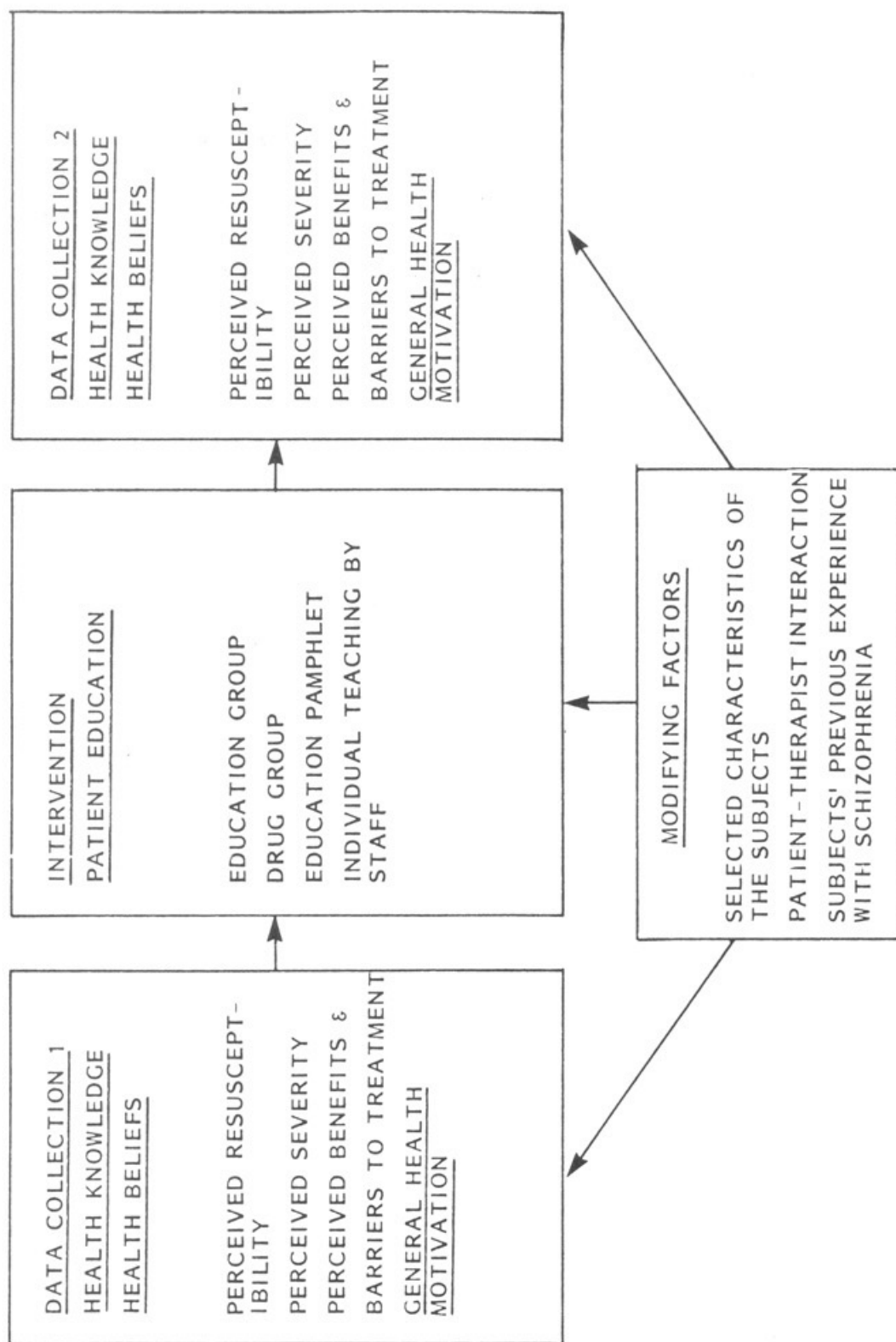


Figure 1. Conceptual framework. Adapted from Becker & Maiman (1975).

METHODOLOGY

A descriptive comparative design was developed for the purpose of determining the effect of educational strategies on schizophrenic inpatients' health knowledge and beliefs. The design included two data collection periods: 1) pre-education, when patients were determined to be mentally competent and able to participate in the study and 2) post education, which occurred at the completion of the hospitalization. The education provided for patients in the study setting consisted of one or more of the following:

- participation in an education group, in which patients were taught about their illness and the positive outcomes of treatment and also were helped to deal with feelings related to their illness;
- participation in a drug group, in which patients were taught about their medications;
- provision of an educational pamphlet, which provided factual information about their illness and identified positive outcomes of treatment;
- individual teaching by staff pertaining to their illness.

The study was conducted at a university affiliated psychiatric hospital. Data collection occurred on several inpatient units where one or more forms of patient education, as outlined above, were integral to the care of schizophrenic patients. A variety of health professionals, primarily nurses, physicians, social workers and occupational therapists were responsible for the ongoing administration of inpatient education, throughout the duration of the hospitalization, generally 10-20 weeks. A small convenience sample of 16 resulted from the data collection.

Instrumentation

The main instrument used in the study was an interview schedule (Interview Schedule A) developed by the investigator based on the conceptual framework and the Standardized Compliance Questionnaire (Sackett, Becker, Macpherson, Luterbach & Haynes, Note 3). In addition, a short interview form was developed by the researcher to elicit the patient's perception of the educational strategies. Data related characteristics of the sample and the subject's medication regimen were collected from the chart.

The interview schedules have not been tested for reliability and validity. As yet, variables of the Health Belief Model have not been tested with a schizophrenic population which places major limitations on both the validity and reliability of Interview Schedule A. However, certain procedures were instituted to increase validity and reliability.

The provision of a structured interview schedule helped to ensure the reliability of the data and also reduced interviewer bias. The pretest conducted by the investigator, and the review of the instrument by two clinical nurse specialists who have expertise in the field, also established the content validity of the interview schedules. Further, reliability of the interview schedules was enhanced, since the investigator conducted all the interviews at both data collection periods.

Methodological Problems

Several methodological problems were encountered during data collection, which resulted in the small sample size. Many patients were unfortunately discharged precipitously prior to the second interview and thus could not be included in the sample. There was also a lack of definitive criteria for the inclusion of patients in the various educational activities, which resulted in diverse clusterings of educational experiences and thus did not allow the use of comparison groups in the study design. As well, there was a decrease in the number of patients admitted to the units with a diagnosis of schizophrenia during the data collection period. These methodological difficulties are often encountered when collecting data in natural settings (Diers, 1979).

DISCUSSION AND FINDINGS

Selected characteristics of the sample studied revealed a population that is representative of other schizophrenic populations described in the literature. The majority of the sample were young, between the ages of 25-34, suggesting that schizophrenia is an illness of adolescents and young adults (Babigian, 1975). Further, most of the sample were single, had not been working for six months or more, were presently unemployed and had from one to nine previous hospital admissions in different institutions. These characteristics reflect the ongoing problems of social adjustment and the lack of health promoting behaviours, which is well documented in the literature (Pyke, 1979; Van Putten, 1978; Jeffries, Note 2).

Knowledge Related To Illness

In this study three areas of knowledge, specifically diagnosis, ability to recognize early return of symptoms and medication, were considered important for patients with schizophrenia.

Diagnosis

Although it remains a controversial issue whether or not to tell the patient the diagnosis of schizophrenia (Masnik, 1974), the majority of patients knew their diagnosis prior to education. This suggests that patients had prior knowledge concerning schizophrenia, possibly from previous admissions or other sources.

The meaning the patient gives to a particular diagnosis is another factor which affects health behaviour. A capacity for understanding the illness will in part determine the meaning an individual attributes to a particular disease. In order to ascertain individual interpretation of schizophrenia, patients were asked to describe in their own words what the diagnosis of schizophrenia meant to them. Appropriate characteristics of schizophrenia which indicated understanding included a general conceptualization of the disease as a serious mental illness, psychosis or biochemical disorder which might arise from certain psychological stresses, as well as the following specific symptoms: hallucinations, delusions, poor reality testing and lability of mood. Patients who could identify at least four such attributes were considered to have a reasonable understanding of the meaning of the disease. Despite the fact that the patient education presented schizophrenia mainly as a biological disorder, few patients identified schizophrenia as a biochemical disorder. Their ability to describe the attributes of schizophrenia tended to improve following patient education, although this improvement was not significant. Generally patient interpretation of schizophrenia was limited. Even after education only 10 patients were able to accurately identify two or more characteristics of schizophrenia.

Return of Symptoms

This area of knowledge appears to be of significance in the treatment of patients for schizophrenia. If patients recognize early symptoms of schizophrenia it is postulated that they will respond promptly to the need for treatment (Hansell, 1978). In this study, application of the McNemar test for difference demonstrated that after patient education significantly more patients were able to recognize the early symptoms of schizophrenia, such as sleep or eating disturbances and/or slight mood lability, rather than the later hard-core symptoms such as hallucinations, delusions or thought disorders ($\chi^2 = 4.08$, $p < .05$). This finding is particularly hopeful as it indicates that patients can learn about early symptoms which may ultimately promote earlier treatment and decrease both the frequency and length of hospitalizations.

Medication

The importance of adherence to medication regimens has been well documented in the literature (May & Tuma, 1976; Hogarty, Goldberg, & Scholer, 1974). As might be expected, all of the sample were taking medication for schizophrenia. It is generally thought that in order to take medication properly, patients should have knowledge of their medication. There was no significant improvement in patients' knowledge of medication following patient education. The findings of the study are in keeping with those of Seltzer et al., (1980) who also failed to find any significant difference in patients' drug knowledge five months after a series of nine educational lectures. This finding is perplexing as virtually all patients reported receiving education in this area; it may be that it was not providing the information patients required or that the strategy of presentation was not appropriate. A further possibility is that learning may have occurred, which the study instrument did not capture.

A summary of the changes that occurred in patients' knowledge after education are presented in Table 1. The findings indicate that patients are able to learn more about their illness, particularly the recognition of early symptoms. However, there were surprising gaps in knowledge, related to medication.

Table 1
Change In Patients' Knowledge Pertaining to their
Illness after Patient Education

Area of Knowledge	Direction of Change		
	+	—	0
Diagnosis	4	1	10 ^a
Return of Symptoms	9*	3	4
Medication	6	3	7

* $\chi^2 = 4.08$, $p < .05$

^a Numbers do not add up the total sample because one subject had not been told the diagnosis and could not respond to questions in this area.

HEALTH BELIEFS AND GENERAL HEALTH MOTIVATION

Almost no change was observed in the specified health beliefs before and after patient education. On the other hand, a number of health beliefs held by the patients were found to be desirable and indicative of healthy outcome behaviours, as described by Becker & Maiman (1975), and thus did not require modification. For example, patients believed they would be resusceptible to another episode of their illness and had confidence in the diagnosis. As well all patients expressed an optimistic and hopeful attitude toward their treatment and reported that they felt their medication could keep them from becoming ill again.

Similar to health beliefs, there was no significant change in general health motivation after patient education. Notwithstanding the lack of measurable change, patients were found to have a high measure of general health motivation, both before and after patient education.

The conceptual framework of the study suggests that health beliefs and general health motivation will have predictive value in relation to health behaviour. The health beliefs and general health motivation of the sample described in the study generally seem to be congruent with those described as desirable in the conceptual framework. Therefore, it might be reasonable to expect that this group of patients would engage in health promoting behaviours. This expectation seems in contrast to general reports from the literature regarding schizophrenic patients' inability to progress toward improved health (Pyke, 1979, Van Putten, 1978; Jeffries, Note 2) and the finding in this study that the majority of the sample had a number of previous admissions. This dichotomy in behaviour and cognition was also documented in studies by Serban and Thomas (1974) and del Campo et al. (1983). As noted previously, del Campo et al. (1983) suggest that this division is typical of a schizophrenic population.

There are several possible explanations for this apparent contradiction. It may be that the educational experiences during previous admissions have resulted in the current level of health knowledge, beliefs and general health motivation. Additional modifying factors such as external stressors and social supports may require exploration and inclusion in a predictive health model for schizophrenic patients. Further, although patients demonstrated some improvement in their level of health knowledge, it is questionable whether they possess sufficient knowledge regarding their illness and treatment, particularly in the area of medication. Another factor to be considered is whether the instrument for data collection was appropriate and whether health

knowledge, beliefs and general health motivation were accurately described in this group of patients. Finally the methodological problems must be taken into consideration.

Several changes which did occur in the measurement of the belief 'perceived severity' are of interest and will be highlighted. These changes may in part facilitate understanding of the apparent contradiction between the described health beliefs of this population and their suggested health behaviours.

Perceived Severity

In order to elicit data concerning the health belief perceived severity, patients were asked to estimate the consequences of the illness, schizophrenia, on their lives. In particular, application of the McNemar test for difference revealed that during their hospitalization patients reported feeling significantly more depressed about their illness over time ($\chi^2 = 4.08, p < .05$). To provide a measure of perceived severity from another perspective, certain illnesses of varying degrees of severity were selected as points of comparison. Patients' estimates of influenza, diabetes and cancer were assessed to be realistic. However, patients' estimates of the severity of schizophrenia in comparison to depression, diabetes and cancer became significantly more serious after patient education ($\chi^2 = 4.267, p < .05$).

These changes in the health belief perceived severity may suggest several hypotheses concerning the findings related to health beliefs and behaviours.

It is possible that patients who recently acquired a diagnosis of schizophrenia are engaged in a grieving process related to the illness. Given the dynamics of such a process, it is not unlikely that the optimal health beliefs represent a significant level of denial related to schizophrenia. The increased levels of depression and perceived levels of severity related to schizophrenia may be indicative of a move toward acceptance and ultimately a more realistic view of the illness.

The nature of this depression was not measured in this study and deserves further exploration. Certainly the issue of inhibiting levels of perceived severity has been examined in the literature (Leventhal, 1970). It may be that despite patients' seemingly optimal health beliefs, the nature of their depression may be so severe that it engenders feelings of helplessness and inhibits health promoting behaviours. Although the data do not allow for definitive conclusions, they emphasize the necessity for further research to explore the nature of patients' depression in relation to their acquired knowledge and beliefs regarding schizophrenia.

CONCLUSIONS

Although educational strategies have been found to be effective in influencing health knowledge, beliefs and behaviours in patients with physical illnesses, such strategies have not been documented as being beneficial to a schizophrenic population. In this pilot study, the effect of patient education on patients' health knowledge and beliefs has been examined. These initial findings suggest that patients are able to report on health knowledge and beliefs pertaining to their illness. There is some suggestion that patient education was effective in increasing schizophrenic inpatients' knowledge pertaining to their illness, although the implications of this knowledge in relation to health beliefs and behaviours require further exploration before they can be fully understood. At this time it is uncertain whether the inclusion of a patient education program for patients with a diagnosis of schizophrenia would be beneficial.

REFERENCES

- Babigian, H. M. Schizophrenia: Epidemiology. In A. Freedman, H. Kaplan & B. Sadock (Eds.). *Comprehensive Textbook of Psychiatry II*. Baltimore: Williams & Wilkins, 1975.
- Becker, M. H. The health belief model and sick role behavior. *Health Education Monographs*, 1974, 2, 409-419.
- Becker, M. H., & Maiman, L. A. Sociobehavioral determinants of compliance with health and medical care recommendations. *Medical Care*, 1975, 13, 10-24.
- Blackwell, B. Treatment adherence. *British Journal of Psychiatry*, 1976, 129, 513-531.
- Brady, J. P., Zeller, W. W., & Reznikoff, M. Attitudinal factors influencing outcome of treatment of hospitalized psychiatric patients. *Journal of Clinical and Experimental Psychopathology*, 1959, 20, 326-332.
- Caplan, R. D., Robinson, E. A. R., French, J. R. P. Jr., Caldwell, J. R., & Shinn M. *Adhering to medical regimens: Pilot experiments in patient education and social support*. Ann Arbor: Research Centre for Group Dynamics Institute for Social Research, 1976.
- del Campo, E. J., Carr, C. F., & Correa, E. Rehospitalized schizophrenics. *Journal of Psychosocial Nursing and Mental Health Services*, 1983, 21, 29-33.
- Diers, D. *Research in nursing*. Toronto: Lippincott, 1979.
- Giovannoni, J. M., & Ullman, L. P. Conceptions of mental health held by psychiatric patients. *Journal of Clinical Psychology*, 1963, 19, 398-400.
- Given, C. W., Given, B. A., & Simoni, L. E. The association of knowledge and perceptions of medications with compliance and health states among hypertension patients: A prospective study. *Research in Nursing and Health*, 1978, 1, 76-84.
- Green, L. W. Educational strategies to improve compliance with therapeutic and preventive regimens: The recent evidence. In R. B. Haynes, D. W. Taylor & D. L. Sackett (Eds.). *Compliance in Health Care*. London: The Johns Hopkins University Press, 1979.

- Hansell, N. Services for schizophrenics: A life long approach to treatment, *Hospital and Community Psychiatry*, 1978, 29, 105-109.
- Haynes, R. B. A critical review of the "determinants" of patient compliance with therapeutic regimens. In D. L. Sackett & R. B. Haynes (Eds.). *Compliance with therapeutic regimens*. Baltimore: The Johns Hopkins University Press, 1976.
- Haynes, R. B., Taylor, D. W., & Sackett, D. L. (Eds.). *Compliance in health care*. London: The Johns Hopkins University Press, 1979.
- Hogarty, G. E., Goldberg, S., & Scholer, N. Drug and sociotherapy in the aftercare of schizophrenic patients. II. Two year relapse rates. *Archives of General Psychiatry*, 1974, 31, 603-608.
- Kirscht, J. P. Research related to the modification of health beliefs. *Health Education Monographs*, 1974, 2, 455-469.
- Lancaster, L. Activity groups as therapy. *American Journal of Nursing*, 1976, 76, 947-949.
- Lee, H. S. Patients' comments on psychiatric inpatient treatment experiences: Patient-therapist relationships and their implications for treatment outcome. *Psychiatric Quarterly*, 1979, 51, 39-54.
- Leventhal, H. Findings and theory in the study of fear communications. In L. Kerbowitz (Ed.). *Advances in Experimental Social Psychology*. New York: Academic Press, 5, 1970.
- Marston, M. Compliance with medical regimens: A review of the literature. *Nursing Research*, 1970, 19, 312-323.
- Masnik, R. Telling a schizophrenic patient his diagnosis. *American Journal of Psychotherapy*, 1974, 28, 452-457.
- May, P. R. A., & Tuma, A. H. A followup study of the results of treatment, *Archives of General Psychiatry*, 1976, 33, 474-486.
- Mikhail, B. The health belief model: A review and critical evaluation of the model, research and practice. *Advances in Nursing Science*, 1981, 4(1), 65-82.
- Powell, B. J., Othmer, E., & Sinkhorn, C. Pharmacological aftercare for homogeneous groups of patients. *Hospital and Community Psychiatry*, 1977, 28, 125-127.
- Pyke, J. Nutrition and chronic schizophrenic. *The Canadian Nurse*, 1979, 75(10), 40-44.
- Seltzer, A., Roncari, I., & Garfinkel, P. Effect of patient education on medication compliance. *Canadian Journal of Psychiatry*, 1980, 25, 638-645.
- Serban, G., & Thomas, A. Attitudes and behaviors of acute and chronic schizophrenic patients regarding ambulatory treatment. *American Journal of Psychiatry*, 1974, 131, 991-995.
- Soskis, D. A., & Bowers, M. B. The schizophrenic experience. *Journal of Nervous and Mental Disease*, 1969, 443-449.
- Statistics Canada, Health Division. Mental health statistics vol. II — Patients on books of institutions, 1976.
- Tagliacozzo, D. M., & Ima, K. Knowledge of illness as a predictor of patient behavior. *Journal of Chronic Disability*, 1970, 22, 756-775.
- Van Putten, T. Drug refusal in schizophrenia causes and prescribing hints. *Hospital and Community Psychiatry*, 1978, 29, 110-112.
- Wing, J. K. The social context of schizophrenia. *American Journal of Psychiatry*, 1978, 135, 1333-1339.

REFERENCE NOTES

1. Jeffries, J. J. *Intensive psychotherapy in schizophrenia*. Unpublished paper presented at the annual meeting — Canadian Psychiatric Association, Saskatoon, 1977.
2. Jeffries, J. J. *Schizophrenia; the views of a specialist*. Pamphlet distributed by the Clarke Institute of Psychiatry, Toronto, 1977.
3. Sackett, D. L., Becker, M. H., Macpherson, A. S., Luterbach, E., & Haynes, R. B. *The standardized compliance questionnaire*. (Prepared for the readers of the Compliance Newsletter), Baltimore, 1976, 1-18.
4. Witt, R. Medication compliance among psychiatric outpatients as a function of locus of control, value placed on health and methods of patient education. *Dissertation Abstracts International*, 1979, 39, 5321-B.

RÉSUMÉ

La schizophrénie et l'éducation des patients

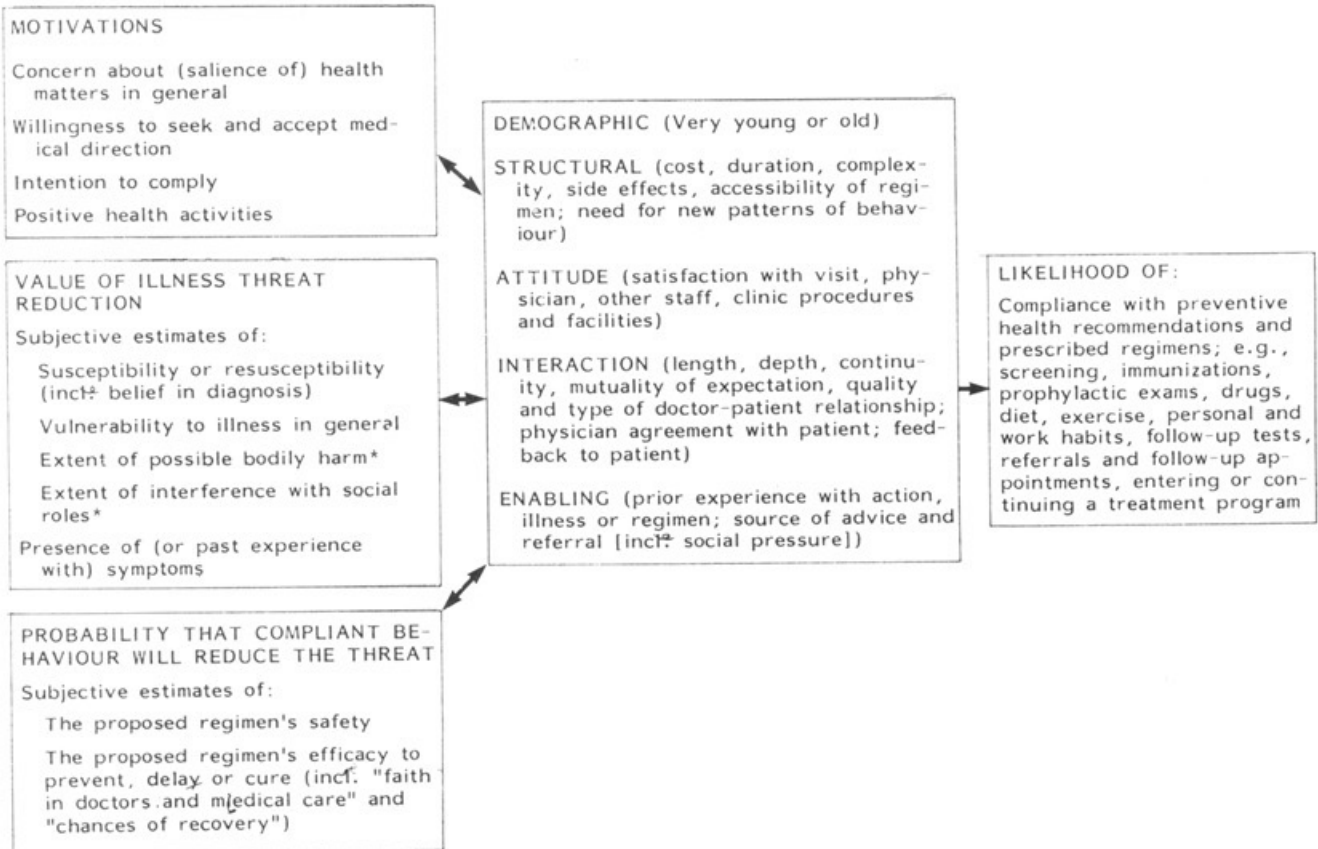
L'objet de cette étude est d'obtenir des données relatives à l'effet qu'un programme d'éducation des patients peut avoir sur les connaissances et les croyances que les schizophrènes hospitalisés entretiennent sur leur maladie. On a choisi le modèle de croyance remanié de Becker et Maiman (1975) en guise de cadre conceptuel de cette étude descriptive. L'échantillon était composé de seize hommes et femmes âgés de 25 à 34 ans, pris par souci de commodité dans divers services d'un hôpital psychiatrique rattaché à l'université de Toronto où l'éducation des patients faisait partie intégrante des soins prodigués aux schizophrènes. Dans cette étude, trois domaines ont été jugés importants pour les patients atteints de schizophrénie, à savoir le diagnostic, l'aptitude à détecter le retour précoce des symptômes, et la médication. Les résultats n'ont indiqué aucune amélioration notable dans les domaines du diagnostic ou de la médication. On a par contre noté une nette amélioration dans l'aptitude des patients à détecter le retour précoce de certains symptômes. On n'a observé à peu près aucun changement, après le programme d'éducation, dans les croyances que les patients entretiennent sur la santé. Toutefois, on a constaté qu'un certain nombre des croyances sur la santé étaient souhaitables et significatives d'un comportement sain et qu'elles ne nécessitaient aucune modification. On s'est également aperçu que les patients avaient un niveau de motivation élevé avant et après le programme d'éducation. Ces conclusions préliminaires ont suscité une recherche plus poussée.

Appendix: Revised Health Belief Model

READINESS TO UNDERTAKE RECOMMENDED COMPLIANCE BEHAVIOURS

MODIFYING AND ENABLING FACTORS

COMPLIANT BEHAVIOURS



* At motivating, but not inhibiting, levels.

Becker & Maiman, 1975, p. 20



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