

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

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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.

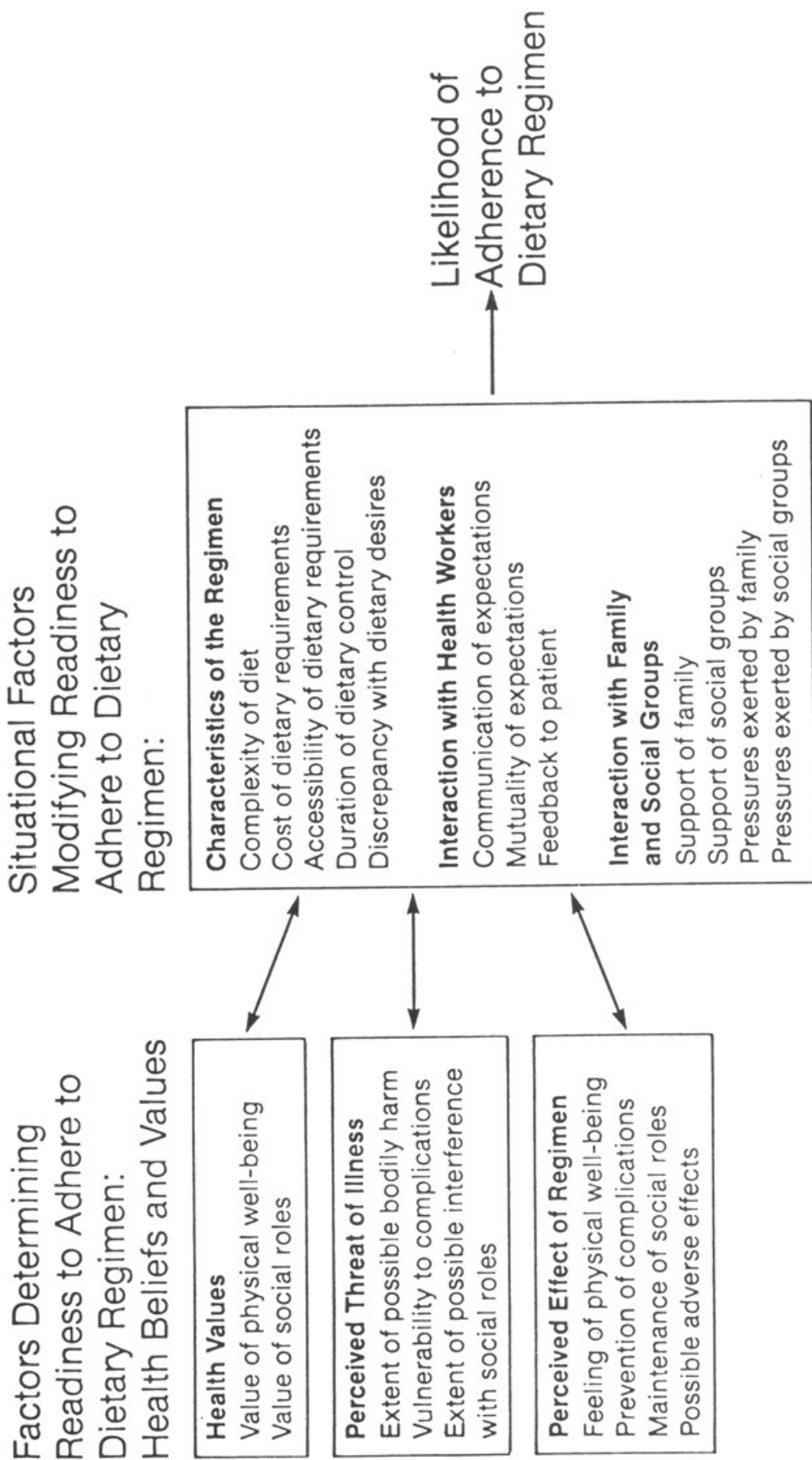


Figure 1. Dietary adherence model.

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.

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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.