

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.

Diane Gendron, R.N., M.S., is a senior tutor, Faculty of Nursing, University of Toronto.
--

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.

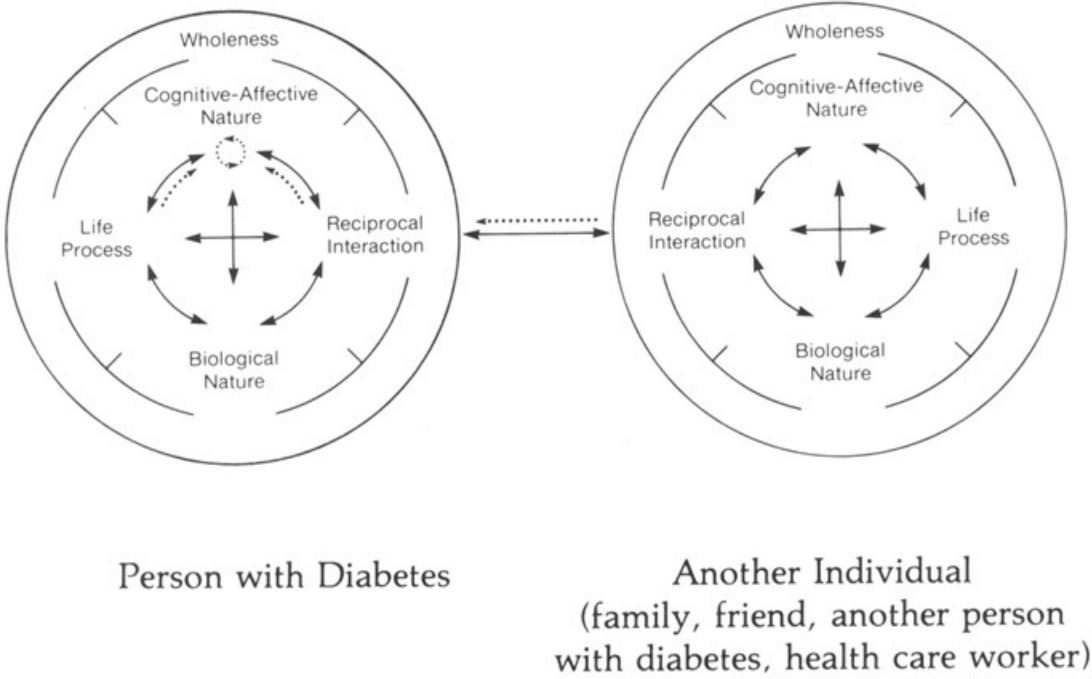


Figure 2. Interactive nature of the high-level concepts of man (University of Toronto Faculty of Nursing, 1981). The dotted lines indicate the relationships discussed in the present paper.

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.