Finding Meaning in Chronic Illness as the Key to Self-Care

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Chez la personne ayant une maladie chronique, l'autosoin est une composante des soins qui en assure l'efficacité. Cependant, plusieurs personnes sont réticents à adopter les comportements d'autosoin. Le but de cette recherche qualitative est de décrire comment les personnes souffrant d'une maladie chronique, dont les symptômes peuvent être contrôlés par le traitement médical, développent la volonté de prendre en charge leurs soins. La méthode inductive pour l'élaboration d'une théorie a été utilisée. Un échantillon sélectif de douze personnes souffrant d'une maladie chronique et neuf infirmières qui les visitaient à domicile a été interviewé. Les résultats indiquent que le processus clé pour la prise en charge des soins est le sens donné à la maladie. Ce processus implique une acceptation de la maladie chronique et une vision de ses effets sur la vie de la personne. La découverte de cette signification lui permet d'assimiler les informations concernant l'autosoin et de percevoir qu'elle a la capacité d'influencer son état de santé.

Self-care is an important element in the successful management of a long-term illness. However, people with chronic illnesses are often reluctant to adopt self-care behaviors. The purpose of this grounded theory study was to investigate the evolution of a readiness to self-manage a nonfatal chronic illness. A purposive sample of twelve individuals with a nonfatal illness whose course can be controlled by treatment were interviewed. In addition, the primary nurse caring for each informant at home was also interviewed. The findings indicate that the key process in self-care readiness was finding meaning in chronic illness. This process involved assenting to the illness and reframing its implications positively. It allowed informants to make sense of self-care teaching and to perceive themselves as self-care agents having some control over their illness course.

This grounded-theory study investigated the evolution of readiness to self-manage a nonfatal chronic illness. Its purpose was to inductively derive a conceptual framework to describe the processes involved in self-care readiness and explain their development among adults with a chronic illness whose course can be controlled through a treatment regimen.

Broadly speaking, self-care refers to the activities that individuals initiate and perform on their own behalf to maintain life, health, and well-being (Orem, 1985). It is especially important for persons with long-term illnesses because they look after themselves at home much of the time (Corbin & Strauss, 1988). Responsibility for managing the symptoms of a chronic illness and administering the treatment regimen often falls on the person who is

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sick, rather than on health-care professionals. However, many people with a chronic disorder hold the traditional sick-role expectation that the treatment regimen will be carried out by health-care professionals. Their estimate of the amount of care they should receive from others often is higher than that of community nurses visiting them at home (Van Agthoven & Plomp, 1989).

The recognition among nurses that the nature of clients' participation is the key element in successful health promotion, health maintenance, illness prevention, and illness management has created an interest in the concept of self-care. Various approaches to self-care have been developed and are being used in nursing (Richardson, 1991). Despite differences in their assumptions, the models agree that readiness for self-care is necessary for its adoption. What readiness for self-care involves and how it develops are poorly understood.

The symbolic interactionist school of sociology guided the assumptions underlying this study. Symbolic interactionism focuses on the meanings of events to people, and the symbols they use to convey that meaning. Blumer (1969) noted that human behavior results from "a vast interpretive process in which people, singly and collectively, guide themselves by defining objects, events and situations they encounter" (p. 132). For people to function in groups, meanings must be shared, and this is accomplished through language and socialization (Chenitz & Swanson, 1986). Because meanings are continually being revised in social interaction, the symbolic interactionist perspective is dynamic and process driven, rather than structural and static. It focuses on psychosocial processes that exist either within the individual or among groups of individuals.

At the outset of a grounded-theory study, the research question is broad. As data collection and analysis progress the investigator's focus sharpens and the question narrows (Glaser & Strauss, 1967). In this study, the following research question emerged: How does self-care readiness develop among persons with a chronic, non-fatal physical illness whose course can be controlled by treatment?

Literature Review

Self-care is a complex concept with multiple meanings. Sometimes it is used to convey client independence from the formal health-care system. At other times, it refers to the performance of behaviors prescribed by health-care professionals. Nurses have tended to view self-care goals as derived mutually by the client and the health-care professional in interaction with one another (Gantz, 1990). Nursing models for understanding self-care behavior indicate that simply teaching clients about self-management of their chronic

illness does not necessarily lead to self-care behaviors (Utz, 1990), and that clients must be ready to use the self-care information they receive. For instance, Orem's self-care deficit theory of nursing pinpoints agency as the key factor in self-care behavior. Self-care agency is defined as the capabilities of individuals that enable them to engage in self-care (Orem, 1985), and involves a repertoire of actions that are set in motion by enabling power components such as motivation. In Steiger and Lipson's (1985) conceptual framework for self-care, motivation is identified as central to the adoption of self-care behaviors. The modeling and role-modeling theory of nursing developed by Erickson, Tomlin, and Swain (1983), postulates that self-care actions depend on a person's emotional ability to mobilize both internal, personal resources and external resources.

Studies of self-management of chronic illness have investigated variables related to self-care. A study of 558 insulin-treated diabetics found that a person's attitude was the most important determinant of self-care (Weerdt, Visser, Kik, & Van der Even, 1990). Chang, Ulman, Linn, Ware, and Kane (1985) investigated the factors that contributed the most to the intention of adhering to a treatment plan in a sample of 26 senior citizens. The researchers identified psychosocial care as the key component. The effectiveness of two models of self-care intervention for persons with arthritis was investigated in a pretest-posttest control-group experimental study. Decreases in perceived helplessness accompanied self-care behaviors, although which preceded which was undetermined (Goeppinger, Arthur, Baglioni, Brunk, & Brunner, 1989). Corbin and Strauss (1988) used the grounded-theory approach to study how people live with a wide spectrum of chronic illnesses. They found that effective management of the trajectory of a chronic illness requires a considerable amount of work, an important part of which involves people's ability to redefine their identity in such a way that they can accept the impact of their illness symptoms on their life. The findings of these studies suggest that clients' readiness for self-care is a prerequisite for using the health information given to them by health-care professionals.

It is unclear which factors are involved in the development of self-care readiness. Orem (1985), for example, considers foundational dispositions such as self-worth, the ability to make decisions, and the ability to learn as prerequisites to the power components in self-care agency. However, there is no one-to-one correspondence between individual foundational dispositions and power components, and their specific relationship to each other is not obvious. As a result, instruments developed to measure Orem's concept of self-care agency have selected different combinations of power components and foundational dispositions (Geden & Taylor, 1991; Hanson & Bickel, 1985; Kearney & Fischer, 1979; McBride, 1987; Riesch & Hauk, 1988). Client

participation in determining therapeutic objectives has been put forward as a possible determinant of self-care readiness, but findings have not been significant. Conway-Rutkowski (1982) examined the literature to investigate the hypothesis that there is a relationship between self-care and patient participation in the nursing process; she concluded that it could not be confirmed. Krouse and Roberts (1989) used an experimental design to examine whether individuals who participate in an actively negotiated process of decision making with the practitioner perceive that they have more control over their care and express greater agreement with the recommended treatment plan. Significant effects were found for an active negotiated style of interaction and perceived control, but not for agreement with the treatment plan.

In summary, readiness for self-care expressed as motivation, attitude, or internal resources has been identified as a significant factor underlying self-care behaviors. However, what makes a person ready to self-manage a chronic illness is poorly understood.

Method

The grounded-theory method was selected for the study. This approach is rooted theoretically in symbolic interactionism, and its purpose is to explain a given psychosocial situation by identifying the core and subsidiary processes operating in it. The core process is the guiding principle underlying what is occurring in the situation and dominates the analysis because it links most of the other processes in an explanatory network. Therefore, grounded-theory is used to generate inductively based theoretical explanations of social and psychosocial processes.

Consistent with the grounded-theory approach, theoretical sampling was used in this study. Thus, data analysis and data collection were carried out simultaneously, and the evolving analysis drove the selection of respondents. Ultimately, informants were selected from three groups: individuals with a nonfatal chronic illness, community nurses caring for these informants, and nurses working with chronically ill patients in other settings.

The sampling process was initiated by interviewing twelve informants with a chronic illness who were being visited at home by nurses of the Extra Mural Hospital of New Brunswick. This hospital provides 24-hour services at home to patients who do not need round-the-clock care. Each informant had a nonfatal chronic illness whose course could be controlled by following a treatment regimen. Their medical problems included insulin-dependent diabetes, renal failure, cardiovascular diseases, and a recent colostomy for bowel cancer. In order to focus specifically on the effect of the chronic illness rather than the effect of aging, the informants chosen were under 65 years of

age. Their ages ranged from 18 to 65, and the modal age group was 40 to 49. Four were francophones and eight were anglophones; four were male and eight were female. The investigator is bilingual and conducted the interviews in the informants' first language.

Analysis of the data obtained from these informants led to further sampling. In order to triangulate by using different sources, each informant's primary nurse from the Extra Mural Hospital was interviewed. The nature of their interventions and their assessment of the informants' responses to their illness and self-care were elicited. In each case, the nurse's description of the client's responses to the illness and to self-care confirmed the account given by the client. Because three of the nurses were each caring for two informants, only nine nurses were interviewed.

At this point in the data-collection and analysis process, concepts were saturated and a conceptual framework emerged. Literature was then selectively sampled and five nurses who work with chronically ill patients in other settings (diabetic clinics and discharge planning) were interviewed. Processes previously observed were compared with those occurring in these situations. Finally, four of the original informants were contacted again to verify the framework.

As noted, following the grounded-theory approach, data collection and data analysis took place concurrently. An open-ended interview schedule was designed for the original interviews with the informants. Questions covered the history of their illness, the medical treatments and nursing care received, their social life, sick-role expectations, their self-care attitudes and behaviors. Some examples of questions asked concerning self-care are: "When you become aware of new symptoms or changes in old symptoms, what do you do about it? Are there things that you do for your health that weren't suggested by a health professional?" Other questions include: "Can you tell me about your treatment plan? Is anyone helping you follow the treatment plan? On the whole, how do you feel that you are managing with your illness?"

Interviews were conducted in informants' homes, lasted from one to two hours, and were tape-recorded. Another schedule was developed for the interviews with the primary nurses who were interviewed in their office. These interviews were also tape-recorded and lasted from one to two hours. Consistent with the method, interview schedules were not rigidly adhered to. Questions were altered and new questions were added as the ongoing analysis sharpened the focus of the study. The interviews with nurses in other settings and the follow-up interviews with the original informants were constructed from a general list of items to be covered.

The data analysis was based on the constant-comparative method. Early data were coded with words that described the action in the setting. As more information came in, codes were revised and the data were recoded. Categories were developed from the clustering of codes that seemed to fit together and were constantly compared with each other to ensure that they were mutually exclusive and covered the behavioral variations. Categories were then linked to form a tentative conceptual framework. As this was being developed, concepts were reviewed, discussed, and modified by colleagues in a grounded-theory seminar.

The emerging conceptual framework was delimited and integrated by memo writing and theoretical coding. Memos were used to record the theory as it developed step by step. Theoretical coding refers to the process of examining data in a theoretical way rather than in descriptive terms.

Before data collection was initiated, the study proposal was approved by the ethics committee at Dalhousie University. Informants were given a verbal and written explanation of the purpose of the study, and each signed a consent form. Anonymity was maintained.

Findings

All nurses who were interviewed believed in the value of self-care and encouraged it. In contrast, all informants initially were reluctant to assume any part of the management of their illness. However, more than half of the informants reported that this had changed, and they now described themselves as self-care agents. A brief overview of the model of self-care readiness that emerged from the data will be provided first and then each of its processes will be described and illustrated with informants' comments (see Figure 1).

Nonaccommodation to chronic illness was the starting point for the development of self-care readiness among informants. This nonaccommodation impeded their assimilation of self-care teachings. It was linked to their view of themselves as either incapacitated or recurringly sick, and therefore dependent on others. The core process mobilizing the evolution of self-care readiness was labelled "finding symbolic meaning in chronic illness." This process was two-dimensional, involving assenting to the chronic illness and reframing its implications positively. These dimensions interpenetrated one another and unfolded together. All informants who were committed to self-care found meaning in their illness but none of the informants who were reluctant to manage their illness themselves did so. Informants who saw themselves as self-care agents felt that they had some control over their illness and that they were normal despite it. They were able to make sense of their nurse's self-care messages.

Nonaccommodation to the Illness

Some informants experienced a dramatic onset of their illness, whereas for others it developed slowly and insidiously. At some point, regardless of how the illness began, informants recognized that it was not following the trajectory of the acute sicknesses they had had in the past. All responded by rejecting the unfamiliar illness pattern. They did this either by seeking a cure, by looking for scapegoats to blame for their situation, or by giving up on life. Many did all three, alternating between them.

Seeking a cure involved a refusal to accept that no medical cure for the illness was currently available. One example of this was a highly educated individual who developed insulin-dependent diabetes. Despite receiving extensive teaching about his illness, he was convinced that taking insulin was a temporary measure to restore pancreatic function. Some informants spent years going from one doctor to another searching for cures for their chronic condition, for symptoms arising from poor self-management of the condition, and for problems arising from treatments, already obtained. One woman who described such a process called herself a "believer in medicine."

When scapegoating, informants rejected their illness with anger and bitterness and looked for someone or something to blame it on. Common scapegoats were God and fate. One young man said, "I just look up and say, 'Why me, Lord?' My sister told me this joke. She said this guy looked up and said, 'Why me, Lord?' The heavens opened up and this voice said 'Because you piss me off.' I'm still waiting for that voice!"

A woman believed that she was destined by fate to experience vicissitudes in her life. She put it this way: "With my luck – I seem to have everything go wrong. Even when I was a kid, if anybody had problems it was me!"

Physicians were another scapegoat for feelings of resentment. "They're not gods" said one woman, expressing her frustration that they could always find a "name" for her health problems but couldn't "do anything about it." Another said, "You have to trust your doctors, but don't trust them to the point that you think they're going to fix you... prepare for the worst."

At times, informants who rejected their illness were so overwhelmed by feelings of futility that they gave up on life. "Look," said one man, "I was going to commit suicide the first time I got hold of a gun." A woman who said, "I drag myself around" described herself as an invalid and gave up going out: "I can't go too far from home because I have to use the bathroom about every half hour — I can't go anywhere." Another informant felt that his life was useless and described himself as being "just a wreck."

Finding Symbolic Meaning in the Illness

Informants who became self-care agents no longer sought a cure, scape-goated, or gave up, but perceived chronicity positively. They found symbolic meaning in chronic illness by assenting to it on the one hand, and by reframing its meaning in their life on the other hand.

Informants who assented to their illness acknowledged its existence, accepted that it was long term, and recognized that it was not currently curable. For instance, one woman who had spent years seeking a cure finally told a physician who had just prescribed a new series of diagnostic tests for her, "Please don't try to cure me any more." She explained this decision: "I don't want anyone to get the idea that I don't want to get better – I do – but I realized then that there's no cure available." For these informants, embracing the painful reality of their illness seemed to diminish its sting. For instance, one woman with diabetes had become effective in managing the symptoms of the illness after years of rejecting the prescribed treatment regimen and poor blood-sugar control. She described diabetes as something that she would always have and said, "It's not too bad really. I'm used to it now and I take it day by day. I have a good life." Another who found his illness a terrible "shock" at first said that he had "adapted to it – I enjoy a professional life and a family life that permits me to live very well."

As informants assented to their illness, they reframed chronicity by reconstruing its implications in a positive way. One method they used, cognitive optimizing, has been identified by Forsyth, Delaney and Gresham (1984). In cognitive optimizing, informants compare themselves favorably with others. Implicit in the comparison is that by having the illness they have been spared something far worse. For example, one informant said, "A lot of others are much worse off than me. I find myself lucky when I see a cripple or, you know, somebody who is really sick."

Another method of finding something positive in the situation was to identify others with similar health problems who are living particularly effective and worthwhile lives. A woman spoke respectfully of a man who had a colostomy like herself. She noted that this man was always written up in the newspaper because of his active involvement in establishing a food bank. Similarly, a young informant with diabetes talked admiringly about a teenager she knows "who's been a diabetic for years and is the captain of the cheerleader squad."

Some informants found that the illness actually improved their life in some way. For instance, one man said that his illness had forced him to reevaluate the quality of his life, and found that he needed to "live" rather than

simply "survive." As a result, he said, he has learned to relax more and has a much happier relationship with his wife and children.

Making Sense of Self-Care

Once informants found meaning in their illness, they were able to make sense of their nurse's self-care teachings by tuning in, integrating, and incorporating these messages. In contrast, non-accommodation to the illness decreased receptivity to the promotion of self-care. One of the earliest models of communication, the Shannon-Weaver model, introduced the concept of "noise" (Shannon & Weaver, 1949). Noise refers to factors that influence or disturb messages while they are being transferred from the source to its destination. In a sense, seeking a cure, scapegoating, and giving up were "noise" because they led informants to tune out, fragment, and avoid self-care messages. The processes involved in making sense of self-care will be presented sequentially, although in reality they overlapped one another.

Tuning in versus tuning out. In the first step toward making sense of self-care, the informant had to register self-care messages by actively listening to them. Finding meaning in the illness was accompanied by a movement from tuning out to tuning in self-care messages. This was illustrated well by the comments of one informant and his nurse, whose accounts corroborated one another's. While rejecting his illness, the informant heard none of the self-care teaching he had received. He explained, "I was completely unconscious – I understood nothing." His nurse said of this period, "Absolutely nothing went in – everything he was taught hit his ear and bounced right back out." The nurse described how he came to hear what she was teaching him: "At a certain point he began telling me that he was looking at his life, readjusting his approach to living, and finding his life better. This is when he began to hear what I was saying."

Integrating versus fragmenting. Another aspect of making sense of self-care was integrating various strands of self-care messages together. Informants began to perceive the management of their illness as a whole. A comment by one woman who sees herself as a self-care agent illustrates this:

I've learned to control my illness – I follow the treatment now and I keep my weight down. I lost 18 pounds. I've been walking once a day, every day, at the same time. Because I'm looking after myself I don't think that I'll get worse.

Informants who were unable to accommodate to their illness sometimes adopted discrete aspects of the self-care messages they received but perceived them in a fragmented fashion. What was retained or dismissed varied considerably. For instance, one woman with a circulatory problem focused on doing her own dressings for recurring leg ulcers but ignored teachings about lifestyle factors. The nurse commented, "It's not that she's ignorant or anything – she's a well versed person and what you tell her is nothing new." This informant had never abandoned her search for a cure. Although she had indeed heard the self-care messages, she discounted them. In contrast, a man who also had leg ulcers as a result of circulatory problems felt very hopeless and discouraged about the effect this was having on his life. He was completely unreceptive to self-care teachings related to the concrete care of the leg ulcers. However, he had registered information about life-style factors, and modified his diet and gave up smoking.

Incorporating versus avoiding. The final step in acquiring the self-care message was finding a way to make the self-care behaviors part of the routine of life. This was difficult because all informants found something about selfcare that was unpalatable to them. Resolution of the incorporation process usually involved discovering ways of making self-care behaviors easier. For instance, a diabetic was unable to give herself insulin. As she began to come to terms with her illness and to reframe it, she renewed her efforts to give herself insulin by establishing a ritual: "I never give myself insulin until I put the bottle back in the box, Never! I always keep the needle covered so I don't have to look at it. I just take the cover off at the end." For another diabetic informant who "loved to eat," incorporating the diet into her daily life was the real stumbling block until she found meaning in the illness. Then she was able to develop a number of strategies, such as buying a diabetic cookbook and making the same meal for her husband and herself. In case of an insulin reaction, she kept a type of candy bar that she disliked so that it would not tempt her otherwise. Nonaccommodation to the illness reduced informants' interest in finding ways to incorporate self-care behaviors.

Defining Self as Agent

Informants who did not find meaning in their illness saw themselves as either chronically incapacitated or, if their symptoms flared up and subsided, recurringly sick. Nonaccommodation prevented them from integrating the illness into their identity in a way that allowed them to see themselves as having some control over it and as being a normal person. In contrast, informants who found symbolic meaning in their illness not only began to make sense of self-care messages, they also began to see themselves as self-care agents. This included a growing belief in their ability to exercise some control over the course of the illness and a perception of themselves as normal rather than as sick or handicapped.

The feeling of control that was part of the informants' perception of themselves as a self-care agent involved a conviction that how they lived and looked after themselves influenced the trajectory of the illness. Informants who felt in control directed their energies toward trying to develop a more effective life style and finding ways to manage the treatment regimen well. One respondent described this process as follows:

I try to create an environment for myself where I feel at ease, an environment where I feel well, because strong emotions affect my illness. I have also taken all sorts of measures to create this environment, a sauna to relax for instance. I don't think my health will deteriorate unless I choose a form of suicide, unless something happens in my life and I am no longer master of myself.

Informants who perceived themselves to be active in managing their illness also explicitly described themselves as normal. The feeling of normalcy incorporated the idea that although the illness was an integral part of them, it did not prevent them from adopting the social roles associated with their stage of life. A comment by an eighteen-year-old respondent illustrates this:

I'm independent and I don't expect to be waited on. At first Mum and Dad sort of went easy on me, but now they get at me just as much as they used to. And I'm comfortable with my friends now, and they don't force me, like "Oh come on you can have it." At McDonald's I'll eat a salad. Diabetics are just normal people who have to take an insulin shot.

Discussion

The analysis indicates that readiness for self-care in chronic illness is a complex and dynamic process. How informants see themselves in relation to their illness appears to be a critical factor in their receptivity to self-care teachings. Lazarus and Folkman (1984) argue that people continuously appraise situations in terms of the potential impact on their well-being. A primary appraisal involves a judgment about whether an event creates an actual or potential harm or loss. A secondary appraisal concerns the options the person has for responding to the situation. Initially, informants appeared to have judged their illness as a harm/loss situation. Some responded by seeking a cure, which reflected a refusal to believe that their illness is chronic. Their reaction is consistent with the findings of previous studies. Whereas some individuals initially respond to the diagnosis of chronic illness with denial (Fredette, 1990; Matson & Brooks, 1977; Redman, 1993), others respond by scapegoating, giving up, anger, and despair; emotional reactions often associated with loss in general (Erickson, Tomlin, & Swain, 1983). It is interesting to note that the process of giving up that characterized some informants is similar to the reaction to loss described by Engel (1968). Both connote a sense of psychological impotence and a feeling that one is unable to cope.

Finding symbolic meaning in a chronic illness by accepting its reality and reframing its implications is no easy challenge, but some informants had done this. This process seems to underlie self-care readiness. It resulted in informants seeing themselves as normal and as having some control over their illness. It may therefore have altered their secondary appraisal of the situation by encouraging what Bandura (1977) refers to as efficacy expectancy, the belief that a person can produce a required outcome. It also appeared to foster what Bandura terms outcome expectancy, the belief that a given behavior will result in a particular outcome.

Limitations

Some limitations of the study need to be mentioned. First, due to theoretical sampling, the findings cannot be generalized to other sample populations. However, Lincoln and Guba (1985) argue that the transferability of qualitative studies depends on the fit of the findings to other situations and is more the responsibility of the person wanting to transfer the findings. Second, the selection of informants was restricted to those with a chronic illness that could be managed through a medical-treatment regimen. The findings could differ in subjects with a terminal illness or multiple sclerosis, which may be difficult to control through medical treatment. As interviews were the principal method for collecting data, the findings depended on the truthfulness and accuracy of the informants.

In order to offset the limitations inherent in qualitative research, the field experience included interviews with nurses as well as patients. There was peer examination of codes and categories. A reflexive journal was kept in which memos were written about evolving hypotheses. A clear decision trail was maintained, and informants validated the analysis. Nonetheless, it is proposed that a future prospective study of newly diagnosed chronically ill individuals would help to verify the temporal relationship between finding symbolic meaning and self-care readiness.

Implications

Gadow (1980) has proposed that nurses be existential advocates who participate with their patients in determining the personal meaning that the experience of illness, suffering, or dying has for those persons. The framework that emerged in this study argues for such a relationship-oriented approach to self-care teaching. An important implication of this study for nursing practice is that nurses should attend to the symbolic meaning that the illness has for the client in order to promote self-care. It suggests that by helping their clients to come to terms with chronicity and reframe the illness, nurses are more likely to be effective in teaching them to be self-care agents.

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