

Disease-Specific Influences on Meaning and Significance in Self-Care Decision-Making in Chronic Illness

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Ce projet de recherche visait à examiner les décisions quotidiennes prises par des personnes atteintes de maladie chronique en matière de soins auto-administrés, dans le but de comparer les démarches de prise de décision suivant les différentes maladies et de cerner les critères par lesquels ces personnes évaluent la qualité des décisions. On a demandé à vingt et un sujets atteints soit de diabète type 2, de VIH/sida ou de sclérose en plaques, et choisis comme spécialistes en matière d'autosoins par leur clinicien, de consigner leurs décisions pendant une période d'une semaine; ils ont ensuite été interrogés en profondeur sur la démarche qui a abouti à leurs choix et sur les facteurs qui les ont influencés. Ce protocole a été répété de manière à obtenir des résultats significatifs et détaillés. Bien que l'on ait pu cerner certains points communs entre les participants relativement à leurs décisions respectives, des différences existent quant au sens et à l'importance qu'ils leur donnent, suivant des attributs propres à chaque maladie : opportunité, biomarqueurs, interaction avec le contexte social, conception des pratiques saines et accès aux renseignements pertinents. Les résultats ont été analysés et comparés dans le but de suggérer des orientations de recherche et des interventions éducatives susceptibles d'améliorer la qualité des décisions en matière de soins auto-administrés chez les patients atteints de maladie chronique, qui tiendraient compte de l'influence des attributs propres à chaque maladie.

The purpose of this study was to investigate the everyday self-care decision-making of individuals with chronic illness for the purpose of developing a comparison of decision-making processes between chronic diseases and to identify criteria by which persons with various chronic conditions evaluate the quality of self-care decisions. A sample of 21 individuals with either Type II diabetes, HIV/AIDS, or multiple sclerosis, who were nominated as expert self-care managers by their clinicians, recorded the decisions they made in their daily self-care over a 1-week period and were interviewed in depth to elaborate on the decisions, the processes by which they made them, and the factors that influenced them. This process was repeated to obtain depth and detail in relation to decisions and decision-making processes. The findings revealed that although participants shared similar elements in their self-care decision-making, they differed in the perceived meaning and significance of their decisions, depending on disease-specific attributes relating to timeliness, biomarkers, interaction within a social context, the construction of healthy practices, and available relevant information. Findings were analyzed and compared to suggest future directions for research and educational interventions to enhance the quality of self-care decision-making in chronic illness by considering the influence of disease-specific attributes in self-care management.

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A major challenge in the self-care management of chronic illness is the need for daily decision-making in relation to medication, diet, and other factors (Hurley & Shea, 1992). Despite the significance of this challenge, the process of self-care decision-making in chronic illness has not been a primary investigative focus (McLeod, 1998). When self-care decision-making has been studied, the emphasis has been on specific decisions such as opting for mastectomy or lumpectomy in breast cancer or responding to a disease-related symptom. Such models do not capture the uncertain, everyday decisions that individuals with chronic illness make, often in the absence of definite symptoms. Further, they provide limited information on context, available resources, or individual perception of the importance of a specific decision within the decision-making process (Hollen, 1994). The development of interventions to foster expert self-care decision-making requires an understanding of what such decision-making might entail (Hernandez, 1991; Maclean, 1991; Maclean & Oram, 1988; Paterson & Sloan, 1994; Price, 1993) — the various processes involved and the criteria that expert self-care decision-makers use in measuring the quality of their decisions. In a study with persons with Type I diabetes (Paterson & Thorne, 2000a, 2000b), we documented such processes in detail and became fascinated with the complexity of everyday self-care decision-making in relation to that disease. However, some of the characteristics of Type I diabetes are unique to that chronic disease, such as the use of a glucometer for feedback on the outcomes of self-care decisions. We therefore extended our inquiry to other chronic diseases, in order to develop a comparative analysis of the phenomenon.

The purpose of this study was to investigate the nature of self-care decision-making in chronic illness for the purpose of developing a comparative analysis of diseases and identifying patient criteria for the evaluation of self-care decision-making across diseases.

We focused our attention on individuals with self-care expertise in relation to a long-standing diagnosis of either Type II (non-insulin-dependent) diabetes, HIV/AIDS, or multiple sclerosis (MS). We selected these three specific chronic diseases because they represented the theoretical variables that might help us interpret differences among the self-care decision-making experiences. While Type II diabetes can include some of the features that were familiar to us from our research in Type I, it is typified by onset in adulthood rather than early in life, and in general it differs from Type I in both trajectory and management. HIV/AIDS was selected on the basis of its representing a rather different social challenge from that of MS or diabetes because of its infectious nature and associated stigma. MS, in contrast to both diabetes and

HIV/AIDS, is characterized by minimal medical intervention coupled with considerable lifestyle adaptation.

Research Method

Our methodological choices were influenced by two assumptions: (1) effective self-care decision-making in chronic illness serves to enhance quality of life, and (2) persons with chronic illness stand to develop expertise in self-care decision-making as they live with the disease. We therefore chose a research method that would enable us to explore self-care decision-making from the perspective of those who engage in it and to consider its multiple coexisting influences. Self-care decisions entail a "range of behaviour undertaken by individuals to promote or restore their health" (Dean, 1989).

Sample

The sample comprised 21 English-speaking individuals over the age of 18 who had been treated for either Type II diabetes, HIV/AIDS, or MS for a period of at least 3 years. These diseases were selected because they represented significant variation with regard to disease trajectory, symptomology, prognosis, treatment, and physiological indicators of the efficacy of self-care. These disease-specific attributes have been determined to influence self-care decision-making in chronic illness (Coates & Boore, 1995; McDonald-Miszczak, Wister, & Gutman, 2001; O'Neill & Morrow, 2001; Paterson, Russell, & Thorne, 2001). The sample included seven persons in each disease category. They were recruited through nomination by primary-care clinicians (such as internists or clinical nurse specialists) as meeting our selection criteria for expertise in self-care management: sufficient knowledge about their disease, the factors that might influence it, and their responses to treatment to make trustworthy self-care decisions in order to maintain or achieve acceptable levels of disease-specific indicators such as HbA1c levels in diabetes or viral load in HIV/AIDS, or symptomatic indicators such as fatigue in MS and HIV. Eligible individuals who indicated a willingness to be contacted were telephoned so that the researchers could clarify the purpose and design of the study and answer any questions. Although all participants were told that they were considered by the nominator to be experts, most expressed a reluctance to be called expert self-care managers, preferring the term "successful" to "expert." One man said: "It is not possible to be an expert, because you are always learning and there is always some new situation to deal with."

All but two of the 13 men and eight women in the sample were Caucasian. As might be anticipated by virtue of disease distribution, the participants varied on several demographic indicators (Table 1). The participants with diabetes were somewhat older and less educated than those in the other two groups, and were more likely to report co-morbid conditions, generally attributable to disease-related complications. Those with HIV/AIDS were generally younger and had more years of education. Those with MS had been diagnosed longer and were more likely to report being divorced since diagnosis. In contrast to participants with diabetes, who typically described themselves as retired, those with HIV/AIDS and MS were more likely to be unemployed and to report significant financial concerns related to their disease and affecting their self-care.

Data Collection and Analysis

Multiple data-collection methods were used to identify the process and possible influences of decision-making. These were: (1) a modified "think-aloud" technique, (2) audiotaped formal interviews, and (3) final focus group session. This combination of methods had been effective in our previous studies (e.g., Paterson & Thorne, 2000a) for eliciting in-depth data on everyday decision-making that are not readily accessible to conscious awareness and are not commonly discussed in traditional interview contexts.

The participants were interviewed immediately prior to the first data-collection period and on two subsequent occasions, within 1 week of each think-aloud recording session. The interviews ranged from 45 minutes to over 2 hours in length. In the initial interview, the participants were asked probing questions with regard to their chronic illness

Table 1 *Demographic Characteristics by Disease*

Disease	Age (years)	Education (years)	Years Since Diagnosis
Diabetes	62–74 x = 66.7	9–16 x = 11.7	4–32 x = 9.9
MS	40–61 x = 50.6	10–17 x = 13.7	8–25 x = 16.6
HIV/AIDS	40–72 x = 50.6	12–17 x = 14.4	3–15 x = 9.7

experience (e.g., What was your response when you first heard your diagnosis?) as well as for demographic and disease particulars, after which the interviewer gave the participant a tape recorder and described the think-aloud method of data collection. In accordance with interpretive description methods (Thorne, Kirkham, & MacDonald-Emes, 1997), questions for subsequent interviews were generated from the analytic framework, previous interviews, and think-aloud transcriptions.

The modified think-aloud technique has been used extensively in the study of decision-making by clinicians (Fisher & Fonteyn, 1994). It has the advantage of being non-intrusive and relatively independent of the researcher's selective interpretation of what is significant to record (Paterson & Thorne, 2000a). The participants were asked to carry a voice-activated tape recorder with them for two 1-week periods over the course of 1 year. Seasonal and life-pattern variations were considered in the choice of data-collection periods, for maximal theoretical sampling.

The participants recorded their decisions regarding diet, medication, physical activity, rest, stress management, skin care, and other disease-related issues. They recorded the reason for the decision, the context of the decision (e.g., who was present), and factors affecting the decision (e.g., stressful event). They also recorded their thoughts on the action chosen (e.g., to contact the physician). Audiotapes of the modified think-aloud sessions were transcribed immediately, and post-think-aloud interviews were scheduled as soon as possible after the recording period (usually 5 days after receipt of the tape). During this interview, the participant was invited to expand upon the logic revealed in the recording and to elaborate on his or her decision-making practices. For example, one participant recorded the following decision: "It was too cold to do my usual walk today so I decided to walk around the basement until I had the same amount of sweat that I get on my walk." During the follow-up interview, the participant was asked such questions as Why did you decide to walk in the basement? How did you know that the activity was equivalent to walking outside? Are there any other activities that you considered equivalent to a walk outside? What would you have done if you couldn't walk in the basement? Although some participants provided less detail in their think-aloud recordings than others, the interview served as a trigger for them to recall further detail and reasoning. Variation in the focus of self-care decisions was evident among the disease groups (e.g., participants with diabetes tended to focus on diet, those with HIV/AIDS and MS on energy conservation).

For the final phase of data collection, the participants were asked to join a focus group attended by people with the same chronic disease. The focus group capitalizes on common themes among people with similar experiences. In the case of the present study it permitted us to test the conceptualizations derived from individuals against the expressed opinions of the group as a whole (Fontana & Frey, 1994). Three participants who were unable to attend the focus group received a written summary of the findings and were invited to comment on them individually.

In keeping with the guidelines for interpretive description, data collection and analysis were conducted concurrently using a constant comparative analytic approach. Building on our research into everyday self-care decision-making in Type I diabetes (Paterson et al., 2001; Paterson & Thorne, 2000a, 2000b), our initial analytic framework oriented this process towards consideration of components of self-care decisions, types of self-care decisions, antecedents, factors affecting decisions, and the criteria by which expertise was determined. This analytic framework provided an initial conceptual focus to the findings and an explicit basis for the evolving comparisons among disease groups.

Findings

The findings revealed that self-care decision-making is a value-laden phenomenon and that the unique nature and character of each chronic disease greatly influence the manner in which it is experienced. The participants judged self-care decisions on the basis of their appropriateness, personal meaningfulness, and significance. Although there were commonalities among the three diseases, the meaning and value attached to self-care decisions were often unique to one disease, particularly with regard to the timeliness of the decision, interaction within a social context, interpretation of biomarkers, the construction of healthy practices, and the availability of relevant information.

Timeliness

One disease-specific factor in the perceived significance and meaning of self-care decisions was their timeliness, particularly with regard to whether the outcome would be immediate, short-term, or long-term. Self-care decisions are largely immediate and short-term in Type I (insulin-dependent) diabetes, because such decisions are necessary to mediate the effect of diet, exercise, medication, and other factors on blood-glucose levels. In Type II diabetes, however, the participants' self-

care decisions were rarely immediate, because they perceived no dramatic consequences to delaying decisions. In HIV/AIDS and MS, immediate decisions were made only in relation to fatigue management or energy conservation ("I had to lie down or I'd never be able to go out later"). The other decisions were occasional (e.g., to take a trip) or one-time (to quit work; to not take a medication or to try a new medication). The timeliness of self-care decisions also affected the number of everyday decisions made within each disease group. While our previous study, among people with Type I diabetes (Paterson & Thorne, 2000a), found a mean of 21 self-care decisions per day in the think-aloud data-collection periods, the present study found a mean of 12 decisions per day in Type II diabetes, four decisions per day in HIV/AIDS, and five decisions per day in MS.

Another aspect of timeliness in self-care decision-making was perceived prognosis. In all three disease groups, self-care involved decisions around the "dailyness" of life in the context of what the future might hold. The future as shaped by the course of the disease influenced the significance and meaning of specific decisions. For persons with MS, for example, decisions forced by a change in mobility (to accept a wheelchair) or career (to take a leave from work) were emotionally charged in that they implied submitting to the progression of the disease rather than merely accommodating a temporary setback. Persons with HIV/AIDS were often aggressive and vigilant about nutrition and wellness in the early stages of the disease but shifted their priorities towards comfort and momentary satisfaction as the disease progressed. As one woman explained, "If I was dying, I'd eat anything I felt like eating." In general, their decision-making was oriented around such issues as how best to make use of the limited quality time they had left. While the participants with diabetes tended to focus their decision-making around meals and other functions in the immediate present, the threat of disease-related complications such as neuropathy eventually became a powerful motivator for considering the long-range implications of their decisions.

Interaction Within a Social Context

The participants described their disease as influencing their social interactions, and their social interactions, in turn, as determining the meaning and significance of their decisions. In HIV/AIDS and MS, for example, the visibility of the disease often exposed the participants to public scrutiny: "You can just feel them staring at you, feeling sorry for you. You start seeing yourself through their eyes and you feel

depressed." Both diseases can involve visible differences that make functioning and interaction complicated. At times, those with MS avoided moving about in public settings for fear of being regarded as "handicapped": "I won't bring my walker with me to the [church] group unless everyone there already knows I have one." Those with HIV/AIDS who had Kaposi's sarcoma avoided situations in which they might be stigmatized because of the disease: "I'm not going to the party. There will be people there who will see my spots." Some participants indicated that visibility did not affect their self-care decision-making once they were able to reframe the situation as non-threatening. For example, a woman with MS stated that at first she had "dreaded" being seen in a wheelchair because of the connotations of helplessness but had learned to view it as "a tool — and I realized fairly quickly that it...allowed me to work, continue to work."

Only those participants with HIV/AIDS consistently reported social context as a focus of self-care decision-making. For them, deciding whether to disclose their HIV status and whether to become activists by participating in the political and advocacy aspects of the disease were integral elements of self-care, because they set the conditions by which they might help to effect long-term gains for people with HIV/AIDS. In many instances, these decisions also involved self-education and research. Although individuals with all three diseases demonstrated some aspects of such participation, only those with HIV/AIDS interpreted it as central to the everyday management of their disease.

The stigma associated with HIV/AIDS influenced the meaning and significance of decisions about disclosure of the disease. The participants said that although those with HIV/AIDS may for years be quite "normal" in appearance and behaviour, they are living with a condition that has been the focus of unprecedented social fear and stigma. They differentiated, however, between the stigma of HIV/AIDS related to chemical dependency and that of "no fault HIV or poor-baby HIV," such as caused by tainted blood or homosexual practices. One participant reported that she had advised a friend with an intravenous drug addiction to say that she contracted her HIV from "a needle stick exposure, to get better treatment."

Biomarkers

Another disease-specific attribute that affected the perceived meaning and significance of self-care decisions was biomarkers, physiological indicators and symptoms typically associated with the disease.

Profound fatigue can be characteristic of both HIV/AIDS and MS. Participants with HIV/AIDS or MS therefore made many self-care decisions in relation to fatigue management and energy conservation, depending on how much they perceived the fatigue as affecting their ability to live the kind of life they wanted to live. Because fatigue tends to be intermittent in HIV/AIDS, persons with this disease often give in to it, rest, and reorganize their lives to accommodate it. In contrast, MS fatigue can be constant and pervasive, so people learn to “push through” it in order to be able to take part in valued activities. In the focus group, the participants with MS identified what they termed the “100-widget theory.” They explained that MS generates a finite allotment of energy for any given day. This awareness of finite energy allotments featured in their decisions related to mobility aids and activities, since using a wheelchair could conceivably free up widgets of energy for activities that “really matter.” People with MS described this monitoring of widgets as like having a “second wheel” constantly running in their heads, counting energy expenditure and warning them when they were getting close to their total daily allotment.

Participants with diabetes were the most familiar with “bodily listening,” using this method and glucometers as mechanisms for fine-tuning the validity and reliability of the somatic cues for physiological status. They stated that this enabled them to detect and treat alterations in blood glucose and thus prevent diabetes-related complications from interfering with their quality of life. They also used these mechanisms to gauge the risk of eating something outside their dietary regime. In addition, they tended to evaluate the quality of their self-care management on the basis of the number and extent of diabetes-related complications they experienced: “I have some neuropathy but that’s all. I think that’s pretty good for someone who’s been diabetic as long as I have. It means I’ve been looking after myself.”

Healthy Practices

While all participants considered healthy practices an aspect of self-care decision-making, the construction of healthy practices differed among the three disease groups. For example, participants with HIV/AIDS and MS regarded food and nutrition as critical factors in their ability to feel as well as possible and to ward off progression of the disease or its complications. In contrast, persons with diabetes focused on eating within strict regulatory guidelines, and their self-care decision-making often related to “cheating” or being “bad” when they failed to follow their prescribed diet religiously. They were much less concerned with

nutrition than with learning how to make a "calculated cheat" by eating foods not included in their diet and how to use medication and exercise to balance this decision. Individuals with HIV/AIDS and MS were more likely to explore health foods and to avoid products that might exacerbate their symptoms, such as fatigue: "I always feel more tired after eating a piece of steak as opposed to chicken or fish." In general, individuals with diabetes were more committed to regular exercise than those with HIV/AIDS or MS, although maintaining physical strength was a concern for all groups. Persons with HIV/AIDS included healthy sexual practices in their commitment to a healthy lifestyle, particularly measures to avoid transmitting the disease. Persons with HIV/AIDS and MS included in their conceptualization of a healthy lifestyle such decisions as: to quit or control smoking, to monitor and reduce stress, to pace and time activities to conserve energy, and to prepare in advance for activities or events that had special meaning.

Information

For all three disease groups, the quantity and nature of information available about the disease and its management influenced the meaning and significance of self-care decisions, particularly decisions about consulting others and adhering to prescribed regimes. The field of diabetes is replete with current, credible information and "textbook protocols" for disease management. Consequently, although the participants with diabetes believed they had unique treatment response patterns, when new issues or problems arose in their self-care management they tended to consult diabetes specialists and to follow their advice, at least initially. If the advice did not result in a resolution, they resorted to experimenting with the prescribed regime or consulting other people with diabetes. "When they tell you this will work, you know that thousands of diabetics have tried it. I give it a try, and if it doesn't work for me, I figure things out for myself."

Although the participants with HIV/AIDS concurred that there is now an extensive database of information on disease management, they pointed out that this information is constantly changing and is often controversial. Most participants in the HIV/AIDS group used computer technology to keep abreast of the constantly changing information in relation to their disease. They stated that health-care professionals "can't possibly keep up with all that's happening in the field" and tended to "shop around" for experts in the field who could answer their questions while acknowledging their own experiential knowledge.

They also relied on each other to validate “rumours and press releases” about HIV / AIDS treatment:

When you have AIDS, everyone has an idea about what works and what doesn't. The doctor I have now, I rely on him to tell me about infections and general things but I wouldn't trust him with drugs — I have a pharmacist that I found on the recommendation of one of my friends who has AIDS too. And sometimes people, like your family, tell you about some herb that will cure you. I don't automatically discount it. I look it up on the Web and look for some articles on it, and I ask around the AIDS community, see what people know and what they think.

Because MS is much less characterized by recommended treatments, persons with MS were more likely than the other participants to explore advice from a series of health practitioners and felt considerably more at liberty to accept or reject medical advice. They emphasized that they were more likely than “strangers, like the doctor” to know “what works.”

Discussion

As articulated by the participants in our studies, self-care decision-making in chronic illness has both general and disease-specific features. Some of the latter influence the meaning and significance of specific self-care decisions as well as how they are made and the priority they are assigned. The specific focus of relevant decisions and the points of tension between standardized advice and individualized choice vary considerably among the disease categories, so that self-care decisions that seem quite familiar to those with one disease might be relatively unfamiliar to those with another.

Grahn, Stigmar, and Ekdahl (2001) demonstrate that meaning positively influences the motivation of people with chronic musculoskeletal disorders to use their personal resources in self-care management. They suggest that quality of life and well-being might improve if nurses, when planning for disease management, were to consider the meaning that people with a chronic disease ascribe to specific aspects of their disease. The present findings provide foundational evidence for such a conclusion in other chronic illnesses.

Our findings also support the notion that practitioners cannot assume that the experience of self-care decision-making is generic. Nor can practitioners assume that common approaches in client education and care management will be equally successful in all chronic diseases. Although our research supports the finding of Kralik, Koch, and Webb (2001) that the chronic illness experience has many common elements

across diseases, it is important for nurses to acknowledge that each disease has unique attributes that influence the meaning and interpretation of specific self-care decisions. Our findings also indicate a need for practitioners to consider not only the immediate meaning of the self-care decision for the person with a chronic disease but also how that meaning is shaped by the person's expectations for the future. Nurses, for example, should consider asking people with chronic illness from time to time how they perceive the trajectory of their disease and how this perception affects their self-care decision-making.

A caution in interpreting these findings is that the features of self-care decision-making that are disease-specific may be a product of not only the disease but also the demographic group in which it is prevalent. For example, the age differential between persons with Type II diabetes and persons with HIV/AIDS may play some role in the discrepancies in reported participation in health-care negotiation and use of technologically based information sources.

Researchers such as Kralik, Brown, and Koch (2001) and Evangelista, Kagawa-Singer, and Dracup (2001) have demonstrated that gender and personal and cultural values influence the meaning that people with chronic illness ascribe to self-care decisions and decision-making. However, this was not a focus of our research. McDonald-Miszczak et al. (2001) found that disease-specific beliefs were predictors of self-care behaviours in people with arthritis, whereas people with hypertension and heart disease were more motivated by general beliefs such as self-efficacy. If the present study had included more disease groups, particularly those that are often asymptomatic (e.g., hypertension), it may have identified additional factors influencing both disease-specific and generic self-care decisions. Therefore, although disease-specific self-care decision-making practices will continue to be of interest to researchers, it is important to ensure that the full range of factors that shape this phenomenon remain open to investigation.

Conclusion

Expert everyday self-care decision-making in chronic illness is a complex, individualized, and dynamic process. The nature and manifestations of each chronic disease determine the particular set of intellectual, social, and behavioural skills that will be developed and refined over time. In varying ways, each chronic disease presents those afflicted with identifiable challenges in interpreting symptoms, managing information, building healthy lifestyle practices, and engaging in social and health-care interactions in order to judge how best to live with their

illness. Both common and disease-specific attributes of the disease will be important elements in our efforts to uncover the inherent meaning and significance of self-care decisions and to uncover and explore the processes by which they are made.

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