Myth of empowerment in chronic illness

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Introduction

Previously it was believed that only health professionals should make decisions about disease management. Now people with chronic illness are invited to be partners in decision making. In Canada, as in other countries, health care agencies and governments promise consumers that ill people will have equal say to that of professionals regarding decisions about disease management. The underlying assumption of this promise is that practitioners should invite participation of patients as equal partners.

Much of the current discussion about the need for patient participation in health care decisions is based on a model of empowerment. Empowerment in this context refers to encouraging people to participate as equal partners in decisions about the health care they receive (Opie 1998). Health care professionals who adopt empowering practices respect patients’ abilities to make decisions, value their input in such decisions, and are able to relinquish control when a patient rejects their advice (Chapman 1994).

Evidence from research about the self-care decision making of people with diabetes is offered here to suggest that, even when active participation of people with chronic illness is promoted by practitioners, the outcome can be a delegitimization of a patient’s ability to participate as an active partner in decisions about care. Our research findings related to self-care decision making have been reported elsewhere (Paterson et al. 1999, Paterson & Thorne 2000a, 2000b).
Background

The idea that empowerment may be a double edged sword, disguising and sometimes justifying paternalistic practices, has recently received attention from critics of health care (Chapman 1994, Opie 1998). Authors purport that simply changing one’s language is not sufficient to effect empowerment; there must also be profound changes in the complex power relations in practitioner–patient interactions (Chapman 1994, Opie 1998, Arksey & Sloper 1999). The primary focus of their critique has been the tendency of practitioners to assume the language of empowerment, including statements that patient participation in treatment decisions is welcome, while at the same time behaving in a manner that implies professional dominance. Although some professionals may support empowerment as a goal of patient participation, their socialization to the ‘practitioner as expert’ model of health care may be so deeply rooted that they proffer patient participation largely as an extension of their power base, rather than as a collaborative venture (Cahill 1998, Arksey & Sloper 1999). They may perceive patients’ attempts to participate in decisions as an invasion of professional territory. For example, participants with cardiac valvular disease reported that although participation was the stated intention of professionals, patients’ involvement was frequently restricted to agreeing to comply with the prescribed regime (Jillings 1992).

One of the most significant studies about the contradictory elements of empowerment in health care was conducted by Opie (1998) in New Zealand. The focus of her research was observation of practitioners and families in 45 team reviews and 10 family conferences. Opie determined that although health care professionals believed that they invited and welcomed family participation, they generally positioned themselves as experts, allocating a subordinate, marginalized role to families. A family’s input regarding decisions about the patient’s plan of care was limited to the agenda established by the health care team. Practitioners often assumed that family members held similar views about the goals and methods of disease management without asking them to validate this assumption.

Similarly, professional dominance is revealed in practitioners’ delegitimization of the knowledge and experience of people who have lived with a chronic illness. The experiential insights that people with long-standing chronic illness bring to interactions with professionals can be considered as authoritative knowledge and a source of personal power (Jordan 1993). Authoritative knowledge of people with chronic illness is what they consider legitimate in making self-care decisions and what they mainly weigh in deciding how to manage their disease, even if it contradicts the advice of practitioners (Nyhlin 1990, Mathieu 1993, Kingfisher & Millard 1998). For example, Primomo (1989) discovered that mothers with diabetes tended to evaluate the success of a management plan based on how it affected the family’s functioning, not metabolic outcomes. Because, at times, practitioners object to self-care practices that are contrary to professional counsel, people with long-standing chronic illness may choose to hide information about their self-care or at times even lie about it (Paterson & Sloan 1994).

Some professionals, particularly physicians, may devalue the authoritative knowledge of people with chronic illness in favour of more ‘objective’ data, such as the results of laboratory tests (Fisher 1991). For example, Kingfisher and Millard (1998) determined that clinic staff often ignored or discounted the questions of the women in their study if those questions were perceived to arise from a lay, rather than a biomedical understanding of disease or treatment. Those with chronic pain frequently encounter practitioners who doubt the legitimacy of their illness and label them as hypochondriacs or as difficult (Howell 1994).

Researchers commonly report that although individuals with chronic illness can develop sophisticated awareness of their body’s patterns and responses that bear little resemblance to the textbook picture, professionals are sometimes reluctant to acknowledge this expertise as credible (Nyhlin 1990, Paterson & Sloan 1994, Paterson & Thorne 2000a). Paterson and Sloan (1994) found that people with chronic illness were often scolded when they told the doctor of a decision they had made in their self-care management. Such practitioner behaviour emanates from professionals’ belief that they know best and that objective evidence, such as physiological indicators or measures of functional integrity, are the only way to determine a person’s health status (Molzahn 1991).

Methodology

Our research was guided by the theory of symbolic interactionism (Blumer 1969). Expert self-care managers were viewed as making decisions in accordance with the meaning, derived from their interaction with others, that the situation or event had for them (Annells 1996). For example, we asked participants to record the self-care decisions they made on a daily basis and to reflect on the meaning and significance of these decisions. The investigation was a 2-years longitudinal study of the decision making processes of 22 adults with long-standing (15 years or more) type I diabetes. The design was emergent in the tradition of Glaser and Strauss (1967) and followed the procedural and theoretical direction of
more recent developments by Thorne et al. (1997). An underlying assumption was that the perspective of the insider, or the person with a disease, regarding everyday self-care decisions is best revealed by interpretive research methods.

The research approach entailed simultaneous and ongoing data collection and analysis as well as systematic efforts to check and refine evolving categories of data that determined further literature review, hypothesis development, sample selection and interview questions (Charmaz 1983). For example, when some participants ‘shopped around’ for practitioners who would facilitate, rather than frustrate, their self-management, the research team conducted a literature review about empowerment and asked participants about what practices would be consistent with empowerment in practitioner–patient relationships. Analysis of the transcripts was guided by traditional constant comparative analytic techniques (Glaser & Strauss 1967).

All 22 participants (14 women and eight men) were Caucasian Canadians who lived in British Columbia, Canada. They ranged in age from 24 to 81 years with a mean of 43 years. They had been diagnosed with diabetes for 15–41 years with a mean of 30 years. Only four had less than high school education; 18 had high school or postsecondary education. Eight participants had one or more diabetes-related complication including nephropathy, retinopathy, atherosclerosis, and neuropathy; 14 had no known diabetes-related complications; 12 lived in urban or suburban areas; the remaining 10 lived in rural areas.

Because a secondary goal of the research was to test and refine the concept of expertise in self-care, we selected participants who were nominated by physicians and those who nominated themselves as expert in self-management of type 1 diabetes. The definition of expert self-management provided to nominators was: the ability to make trustworthy decisions about self-management and to maintain good overall glycaemic control. Eleven people volunteered in response to advertisements in a local newspaper or Canadian Diabetes Association newsletter; they were selected for the study on the basis of self-reports of glycosylated haemoglobin and self-care decision making ability. Another 11 were nominated by five diabetes internists, physicians who were specialists in the field of diabetes medical care.

The data for the study were derived from an initial interview, audiotaped think-alouds, post-think aloud interviews, and a final focus group interview. In the initial interview, the interviewer asked participants to detail their past and current experiences in diabetes self-management including demographic information such as age and duration of diabetes. All individual interviews occurred in the participants’ homes and lasted 90–120 minutes.

Each participant was randomly assigned three periods of 1 week each in the space of a calendar year. During these week-long periods, they were asked to audiotape their self-care decision making using a technique called modified think-aloud or MTA (Fisher & Fonteyn 1995). To permit comparisons between the physician- and self-nominated groups, some participants in each group were given identical MTA schedules. For example, we asked four participants in each group to provide data about self-care decisions during September, immediately following a summer break from work. Think-aloud periods occurred at least 2 months apart to permit sufficient seasonal and other variation to chart the influence of context and other factors on self-management decisions over time. Participants recorded their thoughts, feelings, and decisions made in regard to their diabetes and its management as soon as possible after the decision or situation occurred. For example, one participant recorded, ‘a strange sensation in my stomach that might be because I took my insulin too early before I ran’, while he was training for a marathon run.

Transcriptions of MTA tapes were used as prompts for questions in an intensive interview, called the post-think-aloud interview (PTAI), that occurred within a week of each MTA data collection period. The purpose of the PTAI was to clarify or extend the participants’ statements in the MTA to reveal the complex, multifactorial reasoning of everyday self-care decision making. This entailed repeating participants’ statements about a particular self-management decision in the MTA and asking detailed questions about it. For example, an interviewer asked a participant who had experienced hypoglycemia when shopping and waited until she returned home to eat, ‘What things about this situation influenced your decision to wait? In what situations might you choose to eat right away? How do you know when a decision to wait is safe and when it isn’t?’ The PTAI also included questions that were generated in interviews with other participants or the relevant literature. For example, when two men made a decision to eat more at bedtime because they were afraid of nocturnal hypoglycaemia, the interviewers explored the experience of nocturnal hypoglycaemia with all participants.

A 2-hour focus group interview to share the research findings was held at the conclusion of the study. In each focus group interview, participants in the physician-nominated group were interviewed with others who had been nominated by physicians; those who were self-nominated were interviewed with others who had nominated themselves. During the focus group, the researcher asked participants to comment about the fit of the findings with their experience in managing their diabetes, any findings they perceived as...
surprising or confusing, and anything else that they thought was significant about the findings. Participants agreed with the findings as presented but recommended some re-wording (e.g. ‘Wait and see’ was changed to ‘wait and watch’ to convey the vigilance that accompanies such a response).

Findings

The findings reported here pertain only to data generated from individual accounts, then validated in the focus group interviews. The data revealed that collaborative partnerships with health care professionals were necessary for participants to actively participate in decision making about their diabetes management. Practitioners who fostered such partnerships were described as ‘not necessarily warm and fuzzy’ in their approach but as welcoming and respecting the patient’s input. One man described a practitioner who had fostered his active participation as ‘crusty, no sense of humour, very matter of fact, but willing to really hear me when I say what I think is happening and what needs to happen’. All of the physician-nominated group and only two participants in the self-nominated group had experienced such a partnership. These 13 individuals stated that they had met few practitioners whose practices were empowering. They believed that most practitioners ‘want to be that way’ but that ‘empowerment is a great buzz word that is really hard to actually do’.

Most practitioners in diabetes care were described as competent but ‘more like a professional than a partner’. The participants identified two ways in which practitioners contradicted empowerment: they discounted the experiential knowledge of people who have lived with the disease over time and they did not provide the resources necessary for someone with chronic illness to make informed decisions.

Discounting experiential knowledge

Participants concurred that despite the compassionate and competent manner of many health professionals, their response to patients’ experiential knowledge often betrayed their essential allegiance to professional dominance. Several indicated that attempts to assume an active role in decisions about their care were met at times with obvious scepticism and, at other times, with anger by health care professionals. For example, many participants told stories of episodes where health care professionals encouraged them to participate in decisions about their care, but then immediately discounted what the patient offered in terms of data. One stated:

So I went to him (the physician) and I explained how using a grid system for insulin had worked for me. He listened for a second and then said that he didn’t believe in that for this and that reason and then he said, ‘This is what I use and I think you will find it better.’ He was very nice about it. But it was clear that the discussion was over. He was telling me that he didn’t want to hear what I thought. He is the doctor and what he says goes. I knew that I needed to shop for another doctor who would be more of a partner with me in this (diabetes management).

Participants perceived such incidents as ‘not walking the talk’ of empowerment. They stated that until they know that they can be open with a health care professional about their ideas and experiences, they cannot engage in participatory decision making.

Participants stated that practitioners most often communicate their distrust of experiential knowledge in their response to patients’ statements about what they believed or desired in their disease management. Three participants indicated that some practitioners respond to such statements by emphasizing the unpredictable nature of diabetes and the complexities of diabetes management that are beyond patients’ knowledge and abilities.

He (physician) told me that sure, I could experiment with my insulin if I wanted to. But then he said, ‘I hope you don’t become unconscious in the night if your blood sugar becomes too low. That will be very hard on your wife.’ He knew that I was very afraid of nocturnal hypoglycemia because of that incident in the past. I got the message. He was telling me I should follow what he told me to do. That I would be selfish and irresponsible not to follow his advice to the letter.

Five other participants stated that practitioners convey a distrust of experiential knowledge when they emphasize objective data and dismiss the subjective statements of the person with diabetes. They told of incidents in which practitioners ignored or ‘brushed aside’ what they told the practitioner because of lack of supportive objective evidence.

I tell her (diabetes educator) about how tired I am, how I just don’t have the energy I used to and she says that I am obviously doing well because my A1c (glycosylated haemoglobin) is so good. I am arguing that the new insulin is not for me because I feel terrible and she is saying it’s fine because the numbers say it is.

Still others spoke of how practitioners discounted their experiential knowledge by ‘quizzing’ them about their diabetes knowledge whenever they suggested a change in the prescribed regime.

I get the Spanish Inquisition every time I suggest that we should change what she has ordered. If I don’t think it’s working or I just want to try something new. She fires questions at me about diabetes
or insulin or diet until I don’t get the right answer. Then she says that I am not ready to make a decision like that.

Ten participants stated that their experiential knowledge is discounted when practitioners consider only information derived from textbooks as valid and do not heed data that contradict textbook information. As the participants lived with diabetes over time, their patterns of response to situations and treatment changed and their ability to pick up relevant cues about actual or potential diabetes-related problems increased. These cues were often unlike those typically reported in diabetes texts. For example, participants were often able to identify hypo or hyperglycaemia with such subtle signs as ‘a slight thickening of the gums’, ‘the light looking a little brighter than usual’, or ‘taking a few seconds longer to swing my legs over the bed in the morning’. They perceived textbook signs of hypoglycaemia, such as tremulousness, as ‘too late and mostly irrelevant’.

My body has a way of responding that can’t be found in any book. The books on diabetes say your blood sugar goes up, not down, with stress. It’s the opposite for me when my wife and I fight. If they don’t believe me when I tell them that I am different from the books, I know that they don’t believe that I know anything.

According to the participants, one of the main ways in which professionals may discount the experiential knowledge of people with chronic illness is when they communicate expectations of compliance. ‘They say that they want you to help make decisions about your diabetes but really they only want you to decide to follow what they tell you to do’.

Expectations of compliance were communicated in direct statements (‘He told me that I was not to alter the insulin’), by blaming the person for higher than normal blood glucose levels (‘He accused me of cheating on my diet’), and by monitoring behaviours, such as expecting the individual to return for frequent appointments (‘This doctor wanted to see me every week. He wanted to check up on me to see that I was doing what he told me’) and asking to review records of blood glucose levels and insulin (‘I could have told her what the patterns were but she needed to see them herself’). Participants agreed that when practitioners focus on compliance, they negate an individual’s ability to make decisions and choices that are best for him or her. Several admitted that they lied to practitioners about their self-management strategies because they knew that the professional would disprove of their alterations to a prescribed regime. In fact, these alterations were based on highly sophisticated self-knowledge and experience with the disease and the participants were able to maintain good glycaemic control because of them.

Inadequate resources for decision making

Participants identified a number of resources necessary for them to engage in participatory decision making with practitioners. These included information, time and monetary. Participants stated that the way information is given to persons with chronic illness can affect the willingness and ability to engage in decision making with the practitioner. For example, when practitioners spoke in medical jargon they could not understand, they perceived it as accentuating the power differential between the practitioner and themselves. ‘If he can’t be bothered to talk so I can understand him, he doesn’t really want me to make the decision with him’. Five participants stated that practitioners who do give information irrelevant to their unique situations impair the ability to use that information. A common example was when health care professionals suggested interventions to be used at home without considering the architectural, social or financial constraints that prohibit such a plan.

So he tells me to get a treadmill and to start using it every day. Or to join a gym. Even though I had been going to him for a year, he didn’t remember that I am a student, I have no money, and I live in one room in a friend’s house. I was going to say something to him but I – he didn’t ask me how realistic this was for me. He just assumed that this would work because it’s what other people do.

One of the resources identified as necessary to participatory decision making is time. Time was described in relation to the duration of their relationship with practitioners, the pace and duration of their visits to the practitioner’s office and the duration of waiting time for appointments. Participants stated that lack of time has become a critical issue in recent years as professionals have responded to the ever-increasing demand for chronic illness care. ‘Before I could see my doctor in the same day I phone for an appointment. Now there are so many diabetics. He is so swamped, I am lucky if I see him in 3 weeks’.

Participants agreed that changing practitioners on a frequent basis or being referred to specialists who see the ill person only occasionally, constrains the opportunity for participatory decision making. Because they often saw several practitioners, each of whom had a unique and often limited perspective on the diabetes experience, several participants stated that ‘no one really has the big picture about what I am all about’. They believed that many practitioners learned to trust their experiential knowledge ‘only after they know you and can see that you are serious about your diabetes.’ They perceived most short-term relationships with practitioners as ‘at best, a beginning point but not sufficient time to know each other well enough to work as a team.’ Two commented
that some practitioners ‘never get to know you, even if you go to them for years. They stay distant because that’s their way’.

Participants agreed that participatory decision making is severely constrained whenever practitioners scheduled appointments so that there is little time to ask questions, share ideas or dialogue about available disease management options. They interpreted tight scheduling of appointments as the practitioner being unwilling to include the person with chronic illness as an active participant in health care decisions.

‘Those people are more concerned with getting you through as fast as possible so they can get onto the next patient, than they are about what’s happening to you and what you think.’

One woman who perceived a physician as empowering described him as, ‘taking the time, listening to your questions and ideas, not shrugging off what you say because he’s scheduled appointments back-to-back and doesn’t have the time for you’.

According to participants, practitioners who appeared to lack time frequently convey an allegiance to practitioner ‘as the big cheese’. Several stated that practitioners who appear ‘too much in a hurry when you are in their office and don’t really listen to you’ communicate that they are ‘not open to a patient’s views on things’. They indicated that such practitioners are often unavailable for consultation after hours, do not seem to care about the person’s life beyond the disease (‘They don’t care that you have to live with diabetes in a real world and that there are times when your diabetes isn’t the most important part of your life.’) and generally offer limited responses to their questions. In their opinion, the accessibility of practitioners to answer questions and to consult about a problem was essential to participatory decision making.

The participants concurred that another constraint to participatory decision making was the costs associated with long waiting times for appointments. They often had to leave work, find child care and pay parking costs in order to attend appointments. If they were required to wait for more than an hour to see the practitioner, they were often reluctant to engage in the time that is required to enact participatory decision making. As one participant stated:

‘It is often easier simply to let the professional make all the decisions when the (parking) meter is going and you have already waited most of the day’.

Discussion

At first glance, empowerment seems to offer the promise of active participation of people with chronic illness in disease management decisions but the research findings reveal that practitioners’ practices often carry subtle but significant messages that contradict the tenets of empowerment (Hess 1996). The paradox that exists concerning empowerment of people with chronic illness is that the stated outcomes are so promising that few practitioners would not agree that it is important. However, the contradictions and challenges that exist in the actualizing of the concept mean that the discourse of empowerment in chronic illness health care may continue to be empty rhetoric (Weissberg 2000).

A central theme in our findings points to why participation in health care decisions is problematic for many people with chronic illness, i.e. the practitioner’s positioning as the expert or sole authority. There is a need for further research about the overt and covert ways that practitioners cling to professional dominance and the ways in which practitioners may impede participatory decision making. In contrast to other research that has suggested that people with chronic illness need to develop skills to foster participatory decision making with practitioners, the participants of this research study believed that practitioners should be taught how to enact empowering practices and behaviours. This finding may be a reflection of the ‘expert’ status of the participants. They perceived that they had already developed the skills of participatory decision making. It is poignant, however, that half the participants had been nominated as successful self-care managers by health care professionals, but even they viewed participatory decision making with practitioners as a rare occurrence.

It is apparent in the research findings that practitioners who view time as a commodity to be juggled in health care present barriers to the enactment of empowerment in health care. For example, in the interest of time management and resource efficiency, health care agencies generally organize the workload of practitioners in such a way that it restricts the amount of time available for individuals with chronic illness to interact with health care professionals. This results in the competing goals of time management and active participation in health care decision making (Golin et al. 1996). Time is particularly significant in interactions with clients who have chronic illness because their illness presents complex medical, psychological and social needs that cannot be addressed in the time-efficient medical model of health care in which only the pathology is addressed (Wikblad 1991).

Time with health care professionals is a critical factor in clients being able to assume an active role in decision-making about their care because such a collaborative relationship with health care professionals requires sufficient time to openly explore the client’s concerns and ideas (Rheiner 1995). Often clients with chronic illness who visit health care
professionals health are required to choose between two or more alternatives of a course of action, each involving significant risk to the individual, without sufficient time or information to do so. If people feel unprepared to make a participatory decision and, in addition, are rushed to arrive at a decision, they will probably rely on practitioners to make the decision independently (Rheiner 1995).

The findings suggest that empowerment is more than simply offering a role in decision making to people with chronic illness. Practitioners can extend invitations to people with chronic illness to engage in participatory decision making, but their behaviours and practices may actually inhibit or negate their intended goal. Interpretations of the research findings must consider the unique nature of the participants as expert self-care managers who demonstrated a commitment to active decision making in regard to their disease management. It is unknown if similar findings would occur in a study that focused on the experiences of people with diabetes who were less experienced in living with the disease or who did not express a desire to be actively involved in the management of the disease.

Conclusions

It is evident in our findings that the discourse of empowerment is not always an actuality in the experience of people with chronic illness. Professionals may talk of empowerment in interactions with people with chronic illness, but then act according to a traditional biomedical model. In that model, the professional is the ultimate decision maker or does not offer the resources that the individual needs to be an active participant in decision making. If health care professionals remain uncritical of the rhetoric of empowerment and are not prepared to identify practices that belie participatory decision making in health care, people with chronic illness may experience unmet expectations and frustration in their interactions with practitioners. As well, uncritical adoption of the discourse of empowerment may lull health care professionals into a false sense of security that all people with chronic illness are able to enter into partnerships with practitioners if only the practitioner extends an invitation to engage in participatory decision making.

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References


