To Discipline a “Dog”: The Essential Structure of Mastering Diabetes

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In this article we describe the findings of a study in which the essential structure of mastering diabetes was explored from the patient’s viewpoint, emphasizing the lived experience of adhering and not adhering to a complex treatment regimen for diabetes.

**Keywords:** adherence; chronic illness; diabetes; phenomenology; interpretive methods; health care, users’ experiences; illness and disease; interviews, unstructured; self-care

Patient adherence, by definition, involves two parties: those who prescribe and those who adhere to prescription—the health care professional and the patient. Our interest in doing this study is grounded in the viewpoint that the “problem” of nonadherence in chronic diseases lies in the discrepancy between the “evidence-based best” or recommended treatment, and the “lived best” or the right choice for each patient at any given time.

Nonadherence is of concern to contemporary health care because of its implications for patient health, effective use of resources, and assessment of the clinical efficacy of treatments. It is a controversial, multidimensional, and complex issue that raises ethical questions in health care, and is further complicated with problems in definition and prevalence measurement. The World Health Organization published a report in 2003 summarizing the existing knowledge of adherence in 12 chronic diseases. In the report, poor adherence to treatment regimens is deemed “a worldwide problem of striking magnitude,” with adherence in developed countries among chronically ill patients averaging only 50%. It is suggested that focusing on adherence interventions, and making them more effective, might have a greater impact on the population’s health than any improvement in specific medical treatments (World Health Organization, 2003).

Two perspectives dominate the discourse and research on adherence. Over the course of 40 years, research has predominantly been conducted from the positivist perspective and been patient oriented (although not exploring the patient’s perspective), focusing on etiology, measurement, and intervention strategies to control nonadherence. In spite of extensive studies, adherence rates are not improving. Other aspects of adherence than the patient have been largely ignored in research, and this has attracted criticism. This orientation in research might reflect the dominant ideology, which views nonadherence as irrational and deviant individual behavior (Playle & Keeley, 1998). Others argue that adherence is a socially constructed phenomenon (Fineman, 1991), and reflects paternalism on the part of health care professionals (Bournes, 2000). There has been a call for a broader exploration of the subject, with patients as equal participants, re-evaluating the meaning of adherence from the individual as well as social perspective.

The World Health Organization has embraced both perspectives by calling for a systems approach in addressing adherence issues in chronic illness. It has conceptualized adherence as a multidimensional phenomenon determined by five interacting dimensions: patient-related factors, therapy-related factors, social/economic factors, health system factors, and condition-related factors. Effective interventions have been

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designed and tested, but adherence might not be improving because the interventions are not multifocused (WHO, 2003).

Living with Chronic Illness

Few qualitative studies have focused exclusively on adherence, but adherence is integrated in studies on the lived experience of chronic illness. The insider perspective in chronic illness research represents patients as analysts of their illness experience, active agents in attaining a desired outcome, and experts in self-care (Thorne & Paterson, 1998). Managing the disease is developed into an “illness career” in which the individual learns to respond to changes in health, relationships with health care professionals, and psychosocial aspects of the disease (Price, 1996). The terms “self-care” (Sigurðardóttir, 2005), “self-management” (Koch, Jenkin, & Kralik, 2004; Kralik, Koch, Price, & Howard, 2004), and “decision making” (Paterson, Russell, & Thorne, 2001; Paterson & Sloan, 1994; Thorne, Paterson, & Russell, 2003) are appearing increasingly in the health care literature, reflecting a shift in research perspectives toward valuing and recognizing the patients’ responsibility and autonomous participation in their own care. Thorne and Paterson (1998), however, warn against idealizing the chronically ill person as strong, powerful, and competent, thereby ignoring the continuing need many people have for professional expertise, support, and help.

Paterson (2001b) presented the Shifting Perspectives Model of Chronic Illness, based on metasynthesis of qualitative research reports about living with chronic illness. It suggests that living with the disease is viewed according to how much illness or wellness is in the foreground of a person’s experience. “Perspective” refers to what the person values, believes, expects, and feels about the experience, which determines responses to the illness, caregivers, and illness-affected situations.

Living With Diabetes

It is noteworthy how similar dichotomies color the chronic-illness literature. Ironside, Scheckel, Wessels, Bailey, Powers, and Seeley (2003) state that the space between being acutely ill and being well is poorly documented, although this is where most chronically ill people dwell, trying to “find balance,” a recurrent theme in qualitative studies on life with diabetes (Paterson, Thorne, & Dewis, 1998). The chronically ill describe how they try to “minimize the intrusiveness of the disease” [type 2 diabetes mellitus (DM)] (Koch, Kralik, & Taylor, 2000), to “achieve harmony with oneself” (Delmar et al., 2005), and to be normal within the abnormality of the disease (Öhman, Söderberg, & Lundman, 2003). Development into expertise in diabetes self-management includes learning what works best, to develop body-awareness (Hernandez, Bradish, Rodger, & Rybansky, 1999; Paterson & Thorne, 2000), and finding comfort from the discomfort the disease imposes on the body (Corbin, 2003; Morse, Bottorff, & Hutchinson, 1994; Öhman et al., 2003). Furthermore, people with diabetes deal constantly with a perceived threat (Carpenter, 2005) and warnings about their vulnerability (Weiss & Hutchinson, 2000). Strict glycemic control increases the risk of hypoglycemia, with concomitant disruption of daily routines and social status, and might lead to a conscious, rational decision to keep blood sugar level higher than recommended (Rajaram, 1997; Ritholz & Jacobson, 1998). This dilemma of striving for strict glycemic control and simultaneously avoiding hypoglycemia is a common theme in studies on life with diabetes.

In her grounded theory study, Hernandez (1995) described lived experience of diabetes [type 1] as “integration” of the personal and the diabetic selves. Each person develops lifeways that facilitate or inhibit the three-phase integration process. In the third phase persons have become experts in diabetes, with good glycemic control, sometimes in spite of nonadherence to the prescribed treatment regimen.

Achieving “health within illness” is a fairly recently recognized phenomenon under study (Lindsey, 1996; Whittemore & Roy, 2002) which involves, again, integration of physiological and psychosocial aspects of daily life. Whittemore and Roy (2002) have developed a theory on the process of adaptation to diabetes, synthesized on the concepts of integration, self-management, and health within illness, along with their nursing theory of chronic illness.

Compliance vs. Self-Management

Three qualitative studies were found on the compliance issue from the chronically ill patient’s perspective. The oldest one (Conrad, 1985), on people with epilepsy, revealed how regulating medication represents an attempt to assert control over the condition, and modification of the regimen might be because of negative side effects, the need for independence, destigmatization, or as a proactive behavior for special social circumstances. Conrad concludes that the issue is more one of self-regulation than compliance. Thorne (1990) conducted a grounded-theory inquiry into the meaning of noncompliance. The purpose of noncompliant behavior was seen as twofold: self-protection and maintaining a health
care relationship. Noncompliance was a strategic means to preserve quality of life, and protect oneself from what the participants viewed as inappropriate clinical decisions. Diminished compliance was interpreted as a product of their taking increasing responsibility for their own health; increased confidence entailed diminished confidence in professional expertise. Roberson’s (1992) findings from a qualitative (unspecified) study portray individuals who differ from health care professionals in their interpretation of compliance and goal setting, who develop strategies of self-management which suit their lifestyle, belief patterns, and personal priorities, but might leave them labeled as noncompliant by health care professionals.

Compliance/Adherence

Several nursing studies have been conducted in Finland on compliance/adherence in chronic illness (Kyngäs, 2000; Kyngäs & Lahdenpera, 1999; Toljamo & Hentinen, 2001a, 2001b). These are mainly descriptive studies and many focus on adolescents. The only theoretical model found on compliance relevant to this study was by Kyngäs (1999), based on adolescents’ experience and the author’s own definition of compliance. According to that model, factors that improve compliance are motivation, the results of care, a sense of normality, and adequate energy and willpower for care. Support and fear were also found to affect adherence.

Support is an important part of the lived experience of chronic illness. It can be either informal or formal, with family, friends, and health care professionals playing an important role with accepting, responsive, and person-centered relationships providing optimal conditions for good adherence (Kyngäs, Hentinen, & Barlow, 1998; Olsen & Sutton, 1998; Toljamo & Hentinen, 2001b).

This brief review gives some insight into what life with diabetes involves and how adherence to the treatment regimen is affected by its constructs. The complexity of adherence differs considerably from the simple sounding “blood sugar control” which is expected of the person with diabetes.

A Paradigm Shift in Research and Concept Use

Traditional assumptions about to whom diabetes belongs, who is responsible for the management, and who the expert is are being challenged. There are those who call for a more radical shift in perspectives, with consequent changes in use of terms. Thus, Anderson and Funnell (2000) state that both compliance and adherence are dysfunctional concepts in diabetes care, as diabetes belongs to the person with diabetes, and they call for an empowerment/collaborative approach with a new vision of diabetes education and redefinition of the roles of educators and patients. In recent nursing literature, the terms compliance and noncompliance are hardly used anymore, and adherence and nonadherence rarely, and even then they are defined differently (Kyngäs, 1999). Instead, self-care and self-management are more evident terms, indicating a paradigm shift in research and concept use.

Health care professionals and policy makers are beginning to acknowledge these different perspectives. The World Health Organization (2003) has called for a paradigm shift to redefine roles, re-evaluate assumptions, reorganize services, and (re)learn appropriate communication skills. The authoritarian, “I know best” approach has to be replaced with a different kind of relationship, conceptualized as “partnership” (Gallant, Beaulieu, & Carnevale, 2002), or “empowerment” in the literature. Others criticize the use of such terms and perceive them as potentially arrogant (Thorne, 1990) or even coercive (Powers, 2003) when they are used to bring about compliance, or defined according to the outcome professionals find acceptable. To be effective, such strategies have to involve sharing of control/power by health care professionals, and studies have indicated contradictory outcomes of such intent (Henderson, 2003; Paterson, 2001a). However, partnership as a way in nursing and health care, using dialogues about the patient’s concerns in his or her health circumstances, free from obligations to achieve certain outcomes (Jonsdottir, Litchfield, & Pharris, 2004), is closer to this ideal relationship.

In summary, patient nonadherence to prescribed treatment regimen is an unsolved problem in health care in spite of decades of extensive studies. Patients’ perspectives are rarely addressed in those studies but are explored in this study, using phenomenology to answer the research question: What is the essential structure of mastering diabetes from the patient’s viewpoint, with emphasis on the lived experience of adhering or not adhering to a complex treatment regimen for diabetes?

Method

Population and Sample

The study’s population comprises people with diabetes who have experience adhering and/or not adhering
to their prescribed treatment regimen. Participation in the study was limited to adults with diabetes, diagnosed at least 3 years before, who use insulin injections as part of their treatment regimen.

Access to participants was gained by advertising on the Icelandic Diabetes Association’s Web site and in its free newsletter. Seven people were recruited this way. Another four were contacted on the suggestion of colleagues, and were chosen from a group of people contacted in this way. An informed consent form, in duplicate, was sent by post, with an enclosed stamped envelope, to those who were willing to consider participation in the study. Those who returned a signed copy were considered voluntary participants. They were contacted by telephone and we arranged to meet at a place of their choice—usually in their home.

Ethical Considerations

Confidentiality was preserved by omitting the participants’ names, occupations, ages, and habitations in the findings, as these might imply their identity and make them recognizable to health care professionals. We anticipated problems if colleagues who assisted us in finding participants recognized those in the study. We tried to eliminate this risk by recruiting as many participants as possible through advertisements and, when they were recruited via colleagues, by obtaining more people than necessary and choosing participants from that group. Furthermore, we arranged access to a nurse who could provide support for the participants if they felt a need for such after our meeting.

We sought formal clearance for conducting the study from the National Bioethics Committee in Iceland and notified the Icelandic Data Protection Commission.

Data Collection

The Vancouver School of Doing Phenomenology (Halldorsdottir, 2000) guided the data collection and analysis. Eleven persons participated in the study, six women and five men aged 28 to 84 years, with a mean age of 48 years. (They are referred to as coresearchers according to the Vancouver School.) The participants had been living with diabetes for between 5 and 60 years, with a mean of 29 years. All but one had type 1 diabetes; two had been diagnosed as adults. Six were without diabetes complications; the other five had various complications, such as neuropathy, and vascular diseases resulting in limb amputations, cardiac surgery, and blindness.

Data collection was carried out by the first author through in-depth, unstructured interviews or dialogues, with a total of 16 dialogues (60 to 150 minutes each) with 11 persons, yielding a total of 27 hours of recorded data. She met five of the participants twice, and the others once.

The dialogues were initiated with broad questions about the initial diagnosis and treatment, the experience of adherence and nonadherence, what it was like, and how they felt. Probing was used to ask further questions, and as new themes and experiences unfolded, these were used in subsequent dialogues as probing questions. The experiences were compared, one participant with another, in search of validation of data. Through this interaction the construction of the lived experience of mastering diabetes was created.

Data Analysis

The interviews were transcribed verbatim and analyzed according to the Vancouver School. The transcripts were read, first straight through like a story, then again and again to gain a sense of the experience. The Vancouver School emphasizes “living with the data,” immersing oneself in the data with an open mind, and attentiveness to prevent “premature closure” (a concept developed by Lincoln & Guba, 1985) in the analysis process to increase the quality of the study. Gradually, key statements were identified and coded. When each case had been analyzed an analytical framework was made, grouping key themes and statements together to find the essential structure of the phenomenon for that particular individual. The next step was to verify interpretation of each case construction with the relevant participant, which was done by the first author in the second encounter with those she met twice. She phoned all but one of those she met once and asked them to verify (or not) the analytical framework constructed from the first dialogue which she sent them beforehand. A positive verification came from all of those who replied. Next, all of the dialogues were compared for similarities and differences. The findings were compared with the raw data to find a “proof” in each case for each theme and/or subtheme. All the main themes were confirmed in this way, and each subtheme in some of the dialogues. After having identified the overriding theme which best described the phenomenon, the essential structure was verified with some of the participants and, furthermore, verification was sought from some nonparticipants as well.
The participants confirmed that the findings described their lived experience of mastering diabetes, emphasizing their experience of adherence and nonadherence.

Findings

The experience of mastering diabetes can be understood as a constant attempt to live a normal daily life through balancing the prescribed regimen with physical and psychosocial well-being. This experience is dynamic in nature, changing from one time to another, and the effects of its constructs vary. Most of the participants had personal experience of both adhering and not adhering to the treatment regimen, to the extent of being reprimanded by their doctor. A few of them had been adhering strictly to their regime for decades, with the feedback of having a very acceptable long-term blood glucose level (HbAc1), although their blood glucose control was not always optimal. Furthermore, the findings indicate that the need for autonomy might be threatened by strict adherence. Self-negotiations and competing desires and fears play an important part in the conflicting experience of mastering diabetes. Knowing oneself and respecting the disease without letting it dominate one’s life is the key for successfully integrating what constitutes quality of life and a modified treatment regimen.

Mastering Diabetes: Disciplining the “Dog”

The participants varied in how they situated diabetes in their life, and what the disease and the treatment regimen meant to them. For some, all actions and decisions in life had been made with respect to the disease; it had been allowed to control everything. Although some had found peace with it, others fought a constant battle; still others chose to ignore it as much as they could, with concomitant lack of control. This “relationship” with the disease was quite interestingly summarized as follows:

Living with diabetes is like living with somebody, some furtive companion you can’t get rid of. You can ignore it but it is still there, doing things on its own, even if you’re not aware of it until one day it has already done some damage. Living with someone requires understanding and dialogue, and this dialogue with diabetes has improved with all the new medical knowledge. This can be compared with the relationship between a dog and his master. If you can discipline it, keeping it balanced in order to let it follow you, if you can lead and control scrupulously, without being scared, without letting it control you, then you feel better. Those who manage this have mastered the disease.

All of the participants acknowledged their own responsibility and recognized the importance of respecting the disease, although some refused to be stigmatized as a patient with a disease:

[Diabetes is] not a disease, unless you make it a disease. It’s just a certain lifestyle which I didn’t choose. I was just put there and in order to manage it I primarily need emotional help . . .

Table 1 presents the essential structure of mastering diabetes with main themes and subthemes. The four themes analyzed were recognized by the participants. They are interrelated and the intensity of each

### Table 1
The Essential Structure of Mastering Diabetes

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differs, between persons and within the same person at different times. The experience of paradox between freedom and constraint represents common conflicts within the person with diabetes.

Knowledge, Understanding, and Experience

Knowledge about the triangular interaction between diabetes, insulin, and the body comes from various sources, as do the skills necessary for self-care, such as monitoring blood glucose and injecting insulin. Information and empirical knowledge is juggled with one’s own experience, in an attempt to gain understanding and place oneself within the context of the disease and social context. “Body-listening” is an important part of this process, the “guiding light” in an attempt to find a comfortable and safe condition. Trial and error teach what fits and what doesn’t. Through combining the basic knowledge with real experience, understanding is gained. This process is dynamic and demanding, because of changes in diabetes care, personal development of the person with diabetes, and changes in the disease and bodily responses. Time helps, but in spite of efforts to adhere to the treatment regimen, sudden occurrences of hypo- and/or hyperglycemia are common:

I’ve been learning to listen to my body, but the disease changes, my need for insulin has decreased and my feeling for glucose levels is impaired, so it’s difficult to find the correct dose. Changes in blood sugar are still surprising me.

An important part of adherence is to check and record blood glucose levels regularly, then determine the appropriate insulin dose and inject it correctly. The injections were no hindrance but a totally different story was told about self-monitoring of blood glucose, although modern technology, with built-in memory in the glucometer and quicker measurements, has superseded this hindrance for many and made life easier. An interesting metaphor was offered in these comments:

Checking my blood sugar is like getting a warm pad when my shoulders ache, if I feel funny I will check it. I know I should do so more frequently and since I got my new glucometer I do because it is so simple. Consequently, I have better control over my disease.

Another participant had great problems with this part of adherence: “It just doesn’t fit into my daily life, it’s boring, and it’s a nuisance to carry the stuff around. When you talk about it it’s not a problem, but in real life it just doesn’t happen.” Thus, knowledge, understanding, and experience create the necessary basis for adherence to take place but are not sufficient on their own.

Fighting Fear in the Search for Safety

The experience of adherence is colored with fear or deep concern about diabetic complications and suffering, and the attempt to fight them. There is fear of the consequences of nonadherence, often felt as quite a remote fear. More immediate is the fear of hypoglycemia, which impairs quality of daily life. And there is fear of one’s behavior. When adherence is not manageable, the fear of reality might become overwhelming, resulting in denial and lying to oneself. Fear must be managed because it interferes with quality of life: “Fear is totally destructive for me; it has never encouraged me to change my behavior. I can feel it and it scares me but it doesn’t make any difference.”

Fear of hypoglycemia. Hypoglycemia is common in strict adherence when blood glucose is kept within narrow limits, as well as when the disease is badly controlled. Failure to avoid hypoglycemia leaves the person scared and frustrated, and impairs quality of life to a great extent. This applies to different situations, both at home and away: “I never feel safe when I go to bed, I never know if I’ll wake up hypo or hyper.” This fear affects adherence, because blood sugar might be kept higher than is desirable to prevent hypoglycemia.

Fear of diabetic complications. All the participants realized, if they had not already experienced it, how their nonadherent behavior might increase their risk of diabetic complications; this can affect future plans as well: “I don’t expect to live to be very old, so I don’t plan my retirement savings as I would if there was no diabetes.”

Fear could encourage adherence, although controversial experiences were also described: “I had some preliminary changes in my eyes; I was stressed and scared but not enough to do anything about it.”

Fear of the truth. Most of the participants acknowledged that they had, at some time, deceived themselves when reality hit them hard. During their nonadherent periods they would pretend that things were not so bad, that complications happened to others. Doctors or other health care professionals challenged this. Being told off hurts and “lying to oneself” became “lying to the
doctor,” to modify the truth. Some reacted by failing to bring in records of blood sugar to the doctor, or bringing falsified records. Others tried to make things right before their next appointment by exercising more or eating correctly to bring their sugar down, but did not always succeed:

I got a bad conscience; a long time would pass between appointments because I was trying to manage by myself. It wasn’t working and then the fear would come, and I would go hiding. I just felt so much worse when I went to the clinic and got told off.

Facing the truth can be tough:

The doctor was just telling me the truth, and I couldn’t stand him. But one has to accept the truth and do something about it. It’s either that or letting diabetes take over and win . . . and kill you earlier than otherwise. The choice is mine. But sometimes I just fall into this phase of not wanting to know that I have this disease. And just eat my sweets and my Coke and be like normal people.

Dealing With Conflicting Desires

Dealing with desires is part of the lived experience of adherence, described by all the participants. Desires are part of life and quality of life: to do what we want, right now or in life in general. When adherence is unmanageable, dialogue and negotiations with oneself take place; the desire to do right competes with the wish for normality and giving in to temptations, either “good” or “bad,” which might disturb blood glucose control.

The desire to do right. To do right is a strong element in human beings, but what counts as “right” isn’t always clear. What once was right and wrong in diabetes care is obsolete today. Now, the emphasis is on keeping blood sugar within certain limits and regularly using a glucometer for that purpose. New types of insulin and the glucometer brought a certain freedom and flexibility in diet and activities. The strictness of the treatment regimen varies from one time to another, from one doctor to another. But each person knows when he or she is doing wrong, when the limits are passed which they set for themselves.

The desire to do right is not necessarily connected to the risk of diabetic complications. To do right leads to immediate physical and psychological well-being:

I try to do everything right but I don’t always succeed. I feel so much better when I stick to the rules and manage to stay under 8. . . . I feel light and happy and am determined to do exactly the same again.

Wanting to do right and not managing it results in pangs of guilt and negotiations with oneself, trying to stick to the rules and reward oneself instead: “Now I try to control what I eat and reward myself with good food.”

The desire to do right also affects important decisions like becoming pregnant or dealing with unplanned pregnancy: “I was advised to have my pregnancy terminated, but I was stubborn and refused. Everything changed then, I started taking better care of myself because it wasn’t just me to think of.”

Conflict between desires was common: “Throughout my life this desire to do right would sometimes disappear and get buried under my other desires, desires to do this and that which wasn’t right.”

The desire to be normal. To be normal is also an important element in people. According to the participants, the stigmatization of diabetes threatens the need for normality, and affects the experience of adherence. It was important for them to define themselves as healthy, no different from others, and to avoid attention: “Nobody is supposed to see that anything is wrong with me.”

The participants would try to find a way to be like others and not let the treatment regimen stop them, neither in leisure nor daily life. They did this in diverse ways. There were examples of total negligence in care or struggle with the dilemma of adhering strictly to their regimen, while simultaneously participating in normal social activities like dining out or traveling.

Achieving balance is the ultimate goal, to reconcile the treatment regime with being normal: “My whole life it’s been like this, not wanting to be different, and I can’t get rid of it. I for example always grab a bite or check my blood sugar in privacy.”

Even if the decision has been made to not hide the disease, to aid adherence, the environment, at work for example, might not be receptive: “I’m delaying my checks and injections at work, messing up my routine and not taking as much care, because I’m hiding the disease and its treatment.”

Temptations. Most people have longings for something unhealthy which disturbs blood sugar control. The data indicate that this varies between individuals, as do the risk and values attached to it. Some longings are important in life, others are vices worth overcoming. Dealing with such temptations is an ongoing
process, where limits and boundaries are set to control the temptation or prepare oneself for negative side effects that might be inevitable. Sometimes they take over and push diabetes and the treatment regimen into a shadowed corner, where they are left more or less ignored and neglected. Negotiating with oneself is a common theme here, trying to stay on track and use rewards when deserved.

Those who might be described as adherent had different experiences from the nonadherent. Their desires were not so insistent, so extreme, so difficult to handle. Food and sweets, alcohol, an irregular lifestyle, or extreme activities were not major temptations for the adherent person: “Food is not important to me. I just eat because I have to.” Those who had been nonadherent were bombarded with desires: “One is tempted with so many things and one gives in, indulgence is the word for it . . . .”

If the desires are good and represent something which increases quality of life, they are not seen as worth overcoming. Instead, the person negotiates a way to control blood sugar while enjoying those temptations. Participating in sports is an example of this, which can make diabetes control very difficult: “I have to be very careful, because I tend to become severely hypoglycemic afterwards. But I believe it improves my health otherwise, and would never think of quitting.” Emotional stress at work requires care as well, “but I wouldn’t avoid it just because of the diabetes. Rather take precautions.”

**Freedom or Constraint? The Question of Autonomy**

The experience of adherence is closely related to the feeling of freedom versus constraint. Autonomy gives a sense of freedom, whereas strict adherence to the treatment regimen can be experienced as constraint. It is important to be independent, have self-control, be responsible, and situate diabetes and the treatment regimen in one’s life. Personality and personal characteristics play an important role here. The need for independence and self-determination is interwoven with the need for support and respect—respect from others, but also self-respect and respect for diabetes, to be able to control it.

Strict adherence to a prescribed treatment regimen might threaten the need for autonomy. It might conflict with people’s values and priorities as well as their personalities. A dilemma is created between the need for autonomy, which is challenged by strict adherence, and the threat of diabetic complications, which might leave one dependent and nonautonomous. Many experience “lying to oneself,” denying reality and the consequences of one’s behavior. These might entail physical discomfort today, impairing quality of life, as well as the long-term threat of developing diabetic complications. Periods of denial give way to a sense of responsibility, defining what constitutes quality of life when living with the diabetes regimen, and struggling to achieve that goal. Thus, adherence is perceived as a lifestyle or arrangement of life, so as to achieve quality of life. For the adherent person such a lifestyle quite readily becomes a part of daily life. For the person who has difficulties adhering, this lifestyle or certain elements of it might sometimes be easy, but are more often difficult, sometimes resisted, or even abandoned.

**Independence and being responsible for oneself: The meaning of diabetes.** Those who had considerable experience of nonadherence felt that some elements of the treatment regimen threatened their need for independence. Those who had been adherent had fewer difficulties fitting the regimen into their life, whereas the others put tremendous effort into finding a way to integrate it into daily life, give it priority, and believe in its importance. This was experienced as a struggle between a sense of freedom or constraint: “If my mother had been allowed to control my diabetes, it would have been perfect control . . . but I would have been a dead character, because I just have to learn things myself, I have to make my own mistakes.”

Finding a way to reconcile diabetes self-care with oneself, without jeopardizing independence, is the optimal goal: “Being independent, perhaps it’s a question of looking after one’s health without letting the disease become the center of what my life is all about.” This need for independence can be so strong that control of the disease is perceived as a private matter, no matter what:

This control is my private matter, but it’s a problem how I think I can deal with it, and don’t seek help until very late. I should be able to manage and I know all about it, but then I don’t and end up in hospital, which is very uncomfortable, just like surrendering in a battle.

Those who had been nonadherent for a considerable time in their life looked back and reflected on how they had either changed or were trying to, to take responsibility for their life. Nobody else is going to
do it; controlling their diabetes is “a battle I’m going to win.”

Looking back, and reflecting on what taking responsibility means, was described in the following way:

My complications are my own fault, because I didn’t respect diabetes enough. I chose to cheat on the strict behavior which was expected of me. Living in such a strict and narrow pathway was just so . . . just such a constraint, that for me it wasn’t an option. I wouldn’t have wanted to miss this part of my life, if it had to cost those complications then so be it. I was fully aware that my lifestyle might shorten my life, but I wanted to live fast and just live, even though it was in conflict with the disease. But only the best control is good enough, then you have become responsible for your own health.

Participants set their own rules in their nonadherent periods, some kind of negotiation with themselves, and stuck to those no matter what:

I have tried to create my own balance that suits my life, somewhere between being accurate and careless. I am rather easygoing about it, to prevent it disturbing me too much. I am not interested in living my life through the disease, my diabetes is of no special interest to me.

Self-determination and controlling oneself: The meaning of adherence. Self-determination is an important part of adherence, to follow one’s own convictions regarding the treatment regimen and clarify the meaning of adherence: “Autonomy is so important, because I live by the motto of diabetes not being a disease which needs to be controlled or treated by others. I must be in control myself, otherwise I can’t be independent.”

The threat of diabetic complications does not necessarily encourage adherence to the treatment regimen. Well-being today can be enough encouragement. But there are good days and bad days:

It’s just the phenomenon of feeling well today because my blood sugar is under control which encourages me to keep my plan. On my bad days, like now . . . I can feel how bad this is, but I always have to make the same mistakes again and again, and fall into the bad place to feel how bad it is.

Convictions about self-control might be hidden in self-deception:

I pretend to be convinced that I can control diabetes by treating it lightly and not being dependent on it, then I check my blood sugar seldom and rarely go to see a doctor. Sometimes I consciously bury what I know, in order to enjoy more freedom. But freedom and constraint, there is just a short gap between those two; because I know that if I don’t look after myself my life can become just one big constraint. If my mind goes because of diabetic complications, then I have lost everything, quality of life, autonomy, and independence.

Adherence is about self-discipline and constant awareness—being in control. It is a prerequisite for well-being and being able to enjoy things in life. It takes determination and patience, every day, all the time. Dealing with bad days can, however, ruin good intentions: “I don’t test my blood sugar and don’t care at all. I just eat and eat.” And on good days, none of this is a problem: “I decide that I don’t want to or have to taste this and that. I decide things like this.”

Failure to control blood sugar causes shame and embarrassment. Many of the participants commented on this: “When everything’s out of control I go into hiding. Everybody’s supposed to think everything is fine. I’m just like an alcoholic who hides his drinking. My sugar’s dropping many times a week, and I won’t tell anybody.”

Knowing oneself. Personality and personal characteristics affect adherence, and can either aid or hinder it. To understand oneself and make a realistic plan to improve glycemic control, certain self-examination takes place. Thus, the theme “knowing oneself” was analyzed, when participants described themselves, along with their ability to adhere:

I am a quick-tempered person, extremely energetic, very independent and stubborn. And fussy with food. . . . I was always getting advice about something that just didn’t fit with me like eating bread with cheese. I still don’t eat cheese, never have.

Some people have not had serious problems with adhering to the regimen (although their blood sugar control can be suboptimal):

I think my character just helped me adhere so well. I am a “by-the-clock” person, very conservative and orderly. . . . I can’t change my habits, and I can’t enjoy the freedom that came with the new insulin types, but I don’t feel I’m missing anything.

The value of person-centered support. Support was perceived as an important factor in adherence. Its
sources vary, although family support was frequently mentioned as most important. Support might also come from other people with diabetes, self-help groups, or the Icelandic Diabetes Association. Faith was mentioned as helpful in the search for determination and self-discipline, as was the 12-step program of Overeaters Anonymous. However, support from others can easily turn into its opposite and become interference and criticism, which makes people more vulnerable, threatens their need for autonomy, and might drive them into even more covert behavior. Although support was important, adherence was regarded as a very private matter: “I needed others who knew what I was talking about, but didn’t make any demands.”

Discussion

Within health care services, nonadherence is frequently explained as a matter of knowledge deficit, but our study implies that such an inference is a simplification of a much more complex issue. Although knowledge, experience, and understanding play an important part in adherence, as described earlier, this theme might be the best recognized one in the chronic illness literature, and will not be discussed further here. “Whose responsibility is diabetes care?” has been asked ever since diabetes became a chronic illness (Feudtner, 2003). Nonadherence is frequently referred to by health care professionals as an irrational and irresponsible behavior. However, the findings portray a complex picture of individuals who have acknowledged responsibility for the disease management as being theirs, as well as the diabetic complications they have or might acquire. They fully intend to do their best to control the disease, even though they do not always succeed.

Another interesting finding is how many struggled with management of the disease more or less on their own. One would assume that support from health care professionals would be crucial, but we found that this management is a very private matter and there is a tendency to not seek help until very late. Privacy is an attempt to avoid attention, but also a manifestation of the need for independence, and a strategy to cope with the shame, guilt, and frustration many felt when they were not managing well enough. Hypoglycemia has been described in studies as an extremely private experience which is rarely discussed with others (Ritholz & Jacobson, 1998) and causes negative impact in both interpersonal relationships and views of oneself (Rajaram, 1997). Similar descriptions were found in our study. Some of those who had difficulties with hypoglycemia consciously decided to raise their blood sugar levels in an attempt to prevent such episodes, and many did not ask for help to learn to prevent them. By the same token, hyperglycemia was indicative of their failure to eat correctly.

The Meaning of Diabetes

It is clear from the findings that people with diabetes are subjected to many paradoxes and contradictory messages. They might experience dependency and loss of control over their life when adhering strictly to the regimen, but being nonadherent to the extent of negligence can mean losing control over the body, with subsequent diabetic complications and dependency. Furthermore, they are given two contradictory messages simultaneously: “Be in charge and responsible for your life,” and “Do what we [health care professionals] tell you to do.” The meaning of diabetes relates to the need for independence, according to the findings. Different meanings might be the foundation of differences in dealing with the disease in one’s life, and attaining what Hernandez (1996) and Paterson and Thorne (2000) have termed the phases of “science of one” and “active control,” respectively; i.e., the disease has been integrated into their lives, they have assumed control and decided to take care of themselves.

Disciplining the “Dog”: Mastering Diabetes

In this study, many of the participants personified diabetes as a she (diabetes being a feminine noun in the Icelandic language). Their descriptions might be summarized as follows:

She is here, in my life, an uninvited companion, quiet and invisible initially but constantly pottering around, and dangerous if ignored for long. She must be taken care of and respected, but how much she is allowed to affect my life, threaten my independence and dominate my actions is up to me. I can ignore and neglect her, or give her all my attention and priority, I can fight her and hate her, but also appreciate the restrictions she puts on my “bad” behavior. Respecting her means putting her first, otherwise she will take her revenge.

Those who have reached this stage of understanding have the main goal of taking good care of diabetes, keeping “her” as a disciplined and obedient dog in a back room of the mind. The challenge is to find balance, and balance is a recurrent theme in the
findings as well as in the literature on diabetes experiences. In fact, it is stated to be the determinant metaphor in that experience (Paterson, Thorne, & Dewis, 1998). For the participants in this study the regimen presented an expected behavior, prescribed by health care professionals, to control their blood glucose levels. However, for them, balance and control did not have the same meaning as for their providers. They frequently chose to modify the regimen or be selectively compliant, similar to what Thorne (1990) has described: attending carefully to some aspects of self-management while ignoring others—sometimes occasionally, at other times continuously—and modifying the regimen according to their needs.

Self-Determination and the Meaning of Adherence

Self-determination means to be free to make one’s own decisions without interference from others, and to have those choices respected. The treatment regimen had initially been perceived by many as an oppression (perhaps because it was never negotiated or designed by and for that individual?), causing them to rebel against it. With time they adapted the regimen and learned to value it as a way to take care of diabetes and thus themselves. It became a lifestyle or an arrangement in life to achieve well-being, sometimes easy to follow, a habit, similar to many others. At other times it presented constraints to freedom, because situations and longings arise which require new adjustments, even temporary neglect of the regimen. Some are important and are given priority (many social situations, for example); others are weaknesses that must be resisted, such as carelessness, lack of self-discipline, or “being stupid.” A picture of life characterized by everlasting shifts and lack of stability, even for the most adherent, was portrayed. Life with diabetes is sometimes perceived as a burden, illness, and loss, but at other times normal, healthy, and encouraging. These perceptions vary from one individual to another, but the complexity of feelings exists within each person. It is interesting to compare this with the metastudy of client roles in qualitative research on chronic illness experiences conducted by Thorne and Paterson (1998). In research reports published over a 20-year period, they detected a shift in the conceptualization of individuals with chronic illness, from a focus on loss and burden toward images of more optimistic descriptions. Our findings suggest that within each person all those perspectives exist, changing with time and situations.

Knowing Oneself

The uniqueness of each person was a concept that gradually arose in the dialogues. Differences in people’s values and preferences, characters and personalities, vices and virtues, as well as social circumstances, determine to some extent their experience of the mastering of diabetes, as well as adherence and nonadherence. Controversially, the treatment regimen seems to be universally prescribed for all. It is rarely negotiated or designed by the person with diabetes. Those who had difficulties with adherence found it intolerable to be told how to behave by health care professionals; they knew it perfectly well already. They needed different help from what was on offer. Although they had difficulties conceptualizing it, our interpretation is that they were calling for being recognized and treated as the person they are, and not only the case or the patient, similar to what Liaschenko (1997) has conceptualized as “knowing the patient.”

Fighting Fear in Unrelenting Vulnerability

The fear diabetes imposes on the person’s life is another construct of mastering diabetes, and different fears were described by the participants. Health care professionals confront them with truths which might hurt, and delusions were a common reaction to this. Self-deception or “reality avoidance” are concepts frequently used to describe nonadherent people in a judgmental way. This human way of reacting to a threat is seen when persons persuade themselves to believe what they know is not so, believing two contradictory things at the same time. It thus involves an inner conflict, or the existence of contradiction, which Plato called “true lie,” or the lie “in the soul” (Demos, 1960). Reality avoidance is a concept commonly described in the chronic-illness literature, and Funnel, Anderson, and Arnold (1990) suggest that accepting the reality posed by diabetes and the possible long-term complications provide a sense of unrelenting vulnerability, a state that is resisted or avoided as much as possible.

Competing Desires

Different desires compete within the person and try his or her self-discipline and willpower. Humans are capable of wanting to be different in their preferences and purposes from what they are (Frankfurt, 1971). They are able to form “second-order desires”; that is, wanting to have certain desires or wanting certain desires to be their will (first-order desires are
simple longings for something). This will is the “essence of being a person,” noted Frankfurt (1971), and perhaps it is never as immediate as in adherence, where first- and second-order desires constantly conflict within the person. The desire to be normal is well known in the chronic illness literature, and advances in diabetes management have given many people increased freedom, and made it possible for them to live a more normal life. Although many of our participants praised this change, others had not managed, or were not interested in taking advantage of that freedom, as it involves a more complex treatment regimen. Such negative aspects of advances in medicine are rarely addressed by health care professionals.

**In Search of Autonomy**

Those who had no problems with adherence had always prioritized diabetes: it was in the foreground of their lives. Some managed to care successfully for themselves without jeopardizing their quality of life, whereas others felt that their life had always revolved primarily around diabetes. Still others coped with the restrictions the regimen imposed on them by putting it in the background of their lives, in an attempt to feel free, healthy, and normal. Those findings are in accord with the model of “shifting perspectives” (Paterson, 2001b) which was referred to previously. Within the literature that criticizes noncompliance research and its focus on the patient as the problem, compliance has been conceptualized as primarily a question of professional power (Playle & Keeley, 1998), and a phenomenon socially constructed by health care providers (Fineman, 1991). In this study, the most interesting findings reveal the importance of autonomy. No similar findings were found in other studies with the exception of Conrad (1985, 1987). He has termed the noncompliant patient “in search of autonomy,” and presented the idea of noncompliance and self-regulation as being two conceptual models, two sides (patient’s and provider’s perspectives) of the same coin. Autonomy involves independence, self-determination, and self-care (Redman, 2005). These concepts appeared frequently in the participants’ narratives, although their importance varied between those who had problems and those who had no problems with adherence. The treatment regimen and/or health care professionals can and do threaten patients’ autonomy. Insulin treatment means dependency in itself, and strict adherence to other aspects of the regimen means further dependency for many, disrupting the flow of their daily life. Consequently, they started negotiating the regimen and disease with daily life.

**Conclusions**

The results of this study, guided by hermeneutic phenomenology, has provided insight into life with diabetes and the restrictions imposed on that life by a prescribed treatment regimen. It revealed how people with diabetes exist in the world and how they strive to gain meaning from the experience of being diagnosed with a disease, of being ill, and of being embodied in an ever-unpredictable and changing body. Their interpretations and understanding of living with an ill-fitting treatment regimen differ from the dominant perspective of health care professionals who are appointed to their medical and nursing care. The phenomenological concepts of temporality and spatiality help in understanding how the lived experience of adherence relates to time and space. Will adherence to the treatment regimen give “life to years” and not only “years to life”? The findings also raise questions about the influences society imposes on people, such as whose definition of health and what behavior is acceptable, and how the language is used when treatment regimens are being prescribed and promoted.

The findings of this study give ample reason for continued research, to improve understanding of adherence and how people manage to master diabetes and other chronic illnesses. Suggestions for future research include similar phenomenological studies with the participation of people with chronic diseases other than diabetes, or conditions such as smoking or obesity. Intervention studies addressing the effect of self-help groups on well-being and self-management, as evaluated by people with diabetes, might contribute to further understanding. Intervention studies aimed at assisting patients with identifying their own unique body cues associated with hypoglycemia, hyperglycemia, and normal glucose levels might also be feasible.

**References**


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