PATIENTS' EXPERIENCES IN THE SELF-MANAGEMENT OF DIABETES MELLITUS
Walking a Fine Line

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ABSTRACT

Patients' experiences in the self-management of diabetes mellitus. Walking a fine line.

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This study focuses on how diabetic patients manage to handle their disease, what has facilitated and what has impaired that process. The approach was to use a qualitative method as to enable the researcher to fathom the patients' point of view and to highlight their own experiences. Thus, the study is observational, describing processes, and does not aspire to give verification of the processes described.

The study is based on interviews with 48 insulin dependent diabetic patients including newly diagnosed patients, patients who were regarded as well adapted with long duration of the disease but with no complications, and patients who had developed vascular complications. They were chosen in that way as to give a broad range of experiences representing different faces of the illness.

It was found that the self-management of diabetes is an intricate matter, embodying categories that could be expressed as: Walking a fine line, Managing oneself physically, Managing oneself emotionally, Mastering life, Evading the problem of managing and Managing the health care system.

Walking a fine line elucidates much of the behavioural variation in the data. It captures the patient's need to balance his emotional and physiological state, as well as his interactions with the health care system. Patients who manage the balancing act may enjoy good health but they are walking a fine line between maintaining this state and falling below par.

It seemed that the ideal situation of interaction between the health care system and the patient was not applied in the context of the diabetic patients' everyday life. Patients had to invest considerable effort to cope, not just with their own condition, which is complex enough, but with the system officially charged to help them.

Keywords: diabetes mellitus, self-care, adaptation, coping, concepts of health and disease, grounded theory, interaction.
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by

Kerstin Ternulf Nyhlin

Umeå 1990
Det gäller
att vara lyhörd
för sin egen osäkerhet
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ABSTRACT

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Keywords: diabetes mellitus, self-care, adaptation, coping, concepts of health and disease, grounded theory, interaction.
This thesis is based on the following papers, which will be referred to in the text by their Roman numerals:


V: Ternulf Nyhlin K. Patients with long term diabetes mellitus: managing the health care system. Submitted
INTRODUCTION

Diabetes as disease
When insulin was introduced in 1922 in the treatment of diabetes mellitus, the patients' life expectancy increased by some thirty years (Hellerström 1988). Before that discovery this mysterious metabolic disease often caused the death of the patient soon after onset.

Diabetes mellitus is characterised by deficiencies of insulin action, leading to increased blood glucose concentration, even after fasting. Diagnosis is easy in patients with acute and classical symptoms such as thirst, polyuria and weakness (Kinson and Nattrass 1984). The Turkish physician Aretaeos of Capadokia (130-200 A.D.) coined the term diabetes, and is famous for his precise description: "Diabetes is an awkward affection melting down the flesh and limbs into the urine... the patients never stop making water... Life is short and painful." (Poulsen 1982, p.12).

One of the abiding problems of diabetes has to do with its long-term complications. There is evidence that improved metabolic control could limit those complications in animals (Hägg 1974), although it is not definitely proved in diabetic patients (The Diabetes Control and Complications Trial 1988). In spite of advances in the management of the disease, such as techniques for self-monitoring and improved insulin therapy, diabetic patients still develop late complications, especially of the kidneys, the eyes and the peripheral nervous system. Diabetes mellitus is the second most frequent cause of fatal renal disease. Blindness is ten times more common in diabetic patients, and gangrene and amputations are increased by a factor of twenty compared to nondiabetic individuals (Luft 1986). It carries an increased morbidity in cardiovascular diseases and sexual disturbances. Hospitalization for diabetic patients is twice as common as in age matched groups (Luft 1986).

In Sweden, more than 2% of the population have diabetes mellitus requiring some kind of treatment (Luft 1986). The condition creates a social as well as an economic problem for many people. Nevertheless diabetic patients sometimes are told "that diabetes is not a disease, because they do not become sick until they mismanage themselves" (William Olsson 1986, p.2, my translation).

The two main types of diabetes mellitus are:
Type 1 diabetes, which mainly affects younger individuals, and
Type 2 diabetes, with the highest incidence in older ages.

The disease affects the total life situation of the patient. Type 1 diabetes - which is the concern of the present study - has a more pronounced impact on the patient due to its earlier onset in life and its clear threat of
complications. Eye-complications, for instance, arise in 60% of the patients with insulin dependent diabetes mellitus fifteen years after the onset of the disease (Hellerström 1988), although not all of them are of clinical significance. Also, the daily management of the condition is more delicate when insulin is needed, which is the predicament of Type 1 diabetes.

Increasing attention is being focused on helping diabetic patients to achieve normal or near normal blood glucose levels, in the hope that this will delay the onset and progression of long-term complications (Jacobson et al. 1990). Educational programmes are widely used to teach diabetic patients about management, in the expectation that the increase in knowledge will produce a corresponding improvement in metabolic control (Mazzuca 1986, Dunn and Turle 1987, Ferguson 1988). Research indicates that educational interventions, focused on diabetes management, may not lead to a success in affecting the patients' metabolic control (Karlander and Kindstedt 1983, Lockington et al. 1989). Patient motivation and attitudes are suggested as the altered target of education interventions, which might successfully influence patterns of self-care (Ferguson 1988, Lockington 1989, Jacobson et al. 1990). However, little of the teaching given to diabetic patients is based on any assessment of their informational needs (Ferguson 1988) or on an understanding of their living conditions (William-Olsson 1986). Patients seemingly need help to integrate the demands of the disease into their daily life, to improve well-being (Lundman et al. 1990).

Moreover, to make it even more ambiguous for the patient, recent research indicates that the emphasis on metabolic balance might be exaggerated as a predisposing factor to diabetic long-term complications (The Diabetes Control and Complications Trial 1988).

Considerable resources have been put into medical research in the hope of making daily life easier and delay the onset of long-term complications for the individual patients. Most studies have been linked to metabolic control. Still, diabetic patients in general seem to live with increased blood sugar levels (Derfler et al. 1986).

Derfler et al. (1986) studied the efficacy of diabetes care in a rural area in Austria. They found that 96% of Type 1 and 90% of Type 2 insulin-treated diabetic patients had insufficient metabolic control with values above the upper limit of normal HbA1c (>5.8%). The prevalence of diabetes-associated late complications in Type 1 diabetic patients were: retinopathy 40%, proteinuria 12.7%, macroangiopathy 16.4%, peripheral neuropathy 20.5%. There was an increase of prevalence with the duration of the diabetic condition. Derfler et al. conclude their article with the remark "that present-day routine treatment is not more effective than that in the past. Therefore, to prevent the course of diabetes in patients, a
radical change in therapeutic concept must be designed that includes better
education and motivation to cooperate, at least for insulin-treated diabetics."

This matter of patient's compliance, has been the focus of interest of several studies over the years (e.g. Alogna 1980, Skyler 1981, Newman Smith 1981).

*Diabetes as illness*

Gradually it has occurred to diabetes researchers that the diabetic patient is not simply a passive recipient of health-care but has an active part to play in his or her own management (Jacobson and Hauser 1983, Kinson & Nattrass 1984, p.2). The patient himself is the most important person in the management of his own diabetes. However, diabetic patients need help and support from the family and the health care system in order to balance all those different aspects which are influencing the metabolic control, such as the amount and type of food, insulin and exercise. Also emotional and social factors make impacts on this complex balancing mechanism. As MacRaeHolmes (1986) words it: "Ideally, to minimize fluctuations in blood glucose, a patient should balance not only medication, meal plans, and exercise, but also stress." Diabetes mellitus can be considered a total phenomenon, not merely a metabolic disease.

A simple distinction between illness and disease may clarify this perspective: "The term 'disease' is used to indicate the biological dimension of non-health, which has come to be the focus of medicine - - 'Illness' refers to the more subjective or psychological dimensions of non-health that are generally of more immediate concern to the people experiencing them" (Twaddle 1981). It follows that people can feel ill without having a disease, while others who have a disease, for example diabetes, might feel well (Bond and Bond 1986, p. 201). Sometimes the two definitions of the situation will coincide, for example when a diabetic patient and the physician agree that the person is unwell and diseased, and needs to improve his or her self-care. Even then, though, there may be a conflict between different perspectives on 'managing diabetes'.

Jacobson et al. (1985) have offered tentative suggestions that negative life experiences may indirectly exacerbate progression of late complications. Events that could seem to be of less importance, often called "hassles" by people concerned, may cause failure in daily self-management and be experienced as extremely stressful by the patient.

Lundman et al. (1988) found high levels of tedium in patients with good control and they suggest thoughtfully, that "perhaps the price for good control is, in many patients, exhaustion caused by too high an ambition. This certainly has effects on the general well-being, but it may also prove to be counter-productive to metabolic control in the long-term
perspective". It might be more efficient to slow down somewhat with regard to the demands put on the patient as suggested by Lundman et al. (1988).

Studies on compliance show that at least one-third of patients are noncompliant with drug regimens. Noncompliance tends to be higher when medical regimens are more complex, as is the case with diabetes (Conrad 1985). However, the whole notion of "compliance" has been conceived to solve the provider defined problem of noncompliance (Skyler 1981, Conrad 1985). Most studies on compliance locate the sources of noncompliance in the interaction between the health-care provider and the patient, making interaction skills a necessary part of clinical competence (Conrad 1985, Sanson-Fisher et al. 1989). The concept 'compliance' is derived from a medical perspective, which assumes that health related beliefs are the most important aspects for the patient, and that compliance is a rational decision based on these beliefs.

Some authors emphasize a slightly different approach to diabetes, compared to the traditional medical perspective. For these authors health exists in a state of competition with other factors deriving from the patient's context (Benoliel 1970 and 1975, William-Olsson 1986, Drummond and Mason 1990). Life-style behaviour is interwoven with the real life situations of the persons involved. This view is perhaps best described by Strauss et al.(1984 p. 19): "while chronically ill people carry a burden of symptom and regimen management, shared to some degree with spouses at least, they also are doing life's other work (domestic, office or school, or other 'work'), which in turn impacts on, is impacted by, and is all intertwined with the medical tasks themselves".

In a study from Scotland the constraints for keeping to the recommended regime, recognized by diabetic patients as imperative, appeared to be more diverse than those recognized by general practitioners (Drummond & Mason 1990). These constraints included family relationships, self-image, and emotional equilibrium.

Cameron (1987), in an article about chronic illness and compliance, stresses the view that patients assess recommended treatments on how well they can be integrated into their lives. How the patient perceives the situation determines whether or not he will comply. According to Cameron (1987): "health professionals may be working against themselves if they cut off patient participation by assuming the traditional style of patient-professional interaction (this assumes a passive, dependent patient and independent, authoritarian professional)".

Some 'grounded theory' (Glaser and Strauss 1967, Chenitz and Swanson 1986) reports by researchers circling around Strauss have focused on chronic illness and how individuals redesign their lifestyles to manage the

Patients' interaction with the health care system
Engel (1977) challenged the usefulness of the traditional bio-medical model for medicine, and recommended that it be replaced by an equally scientific model that he referred to as a biopsychosocial model. According to Engel (1977): "A medical model must also take into account the patient, the social context in which he lives, and the complementary system devised by society to deal with the disruptive effects of illness, that is, the physician role and the health care system. This requires a biopsychosocial model".

Jacobson and Hauser (1983) argue similarly, with regard to diabetic patients, that the physician should be able to help the patient set reasonable goals for self-care, and "to provide a backdrop of acceptance if the patient does not achieve them either because of physical, social, or psychological limitations".

Smith and Pettegrew (1986), however, remarked upon the biopsychosocial model that: "communication is still viewed fundamentally as the exchange of information; social psychological data supplements medical information (...) the locus of influence remains with the doctor; the doctor still knows best". Instead of this paternalism, they argue for 'shared decision-making' as a desired end, where the relationship between doctor and patient involves "some mix of caring, respect and expectations about each other".

Sätterlund-Larsson (1989), drawing on e.g. Gilligan (1982) and Mishler (1984) discusses the concept of "voice" as a clarifying concept for the understanding of interactions between patient and the health care system. In attempting to make clear the notion of "voice", Mishler explains:

"As I understand it, a voice represents a particular assumption about the relationship between appearance, reality, and language, or, more generally, a 'voice' represents a specific normative order"(p. 63).

Mishler makes a distinction between the "voice of the lifeworld" and the "voice of medicine", which represent different frameworks or different ways of conceptualizing and understanding patients' problem. The two concepts were used in analyses of the discourse of medical interviews. Mishler found medical interviews to be "arenas of struggle, marked and shaped by conflict between the voices of the lifeworld and of medicine. Typically, the voice of the lifeworld was suppressed and patients' efforts to provide accounts of their problems within the contexts of their lifeworld situations were disrupted and fragmented" (Mishler 1984, p. 190).
'This leads into Freire (1972), a Brasilian educator, who's "Pedagogy of the oppressed", inspired many health professionals to try to base dialogues with patients on the latters' subjective life situations. The health care system was criticized during that time, perhaps most fiercely by Illich (1975) who's thesis was that "the medical establishment has become a major threat to health". Illich was later questioned by Navarro (1975), who claimed that Illich's conclusions affected under-privileged groups in society, like the chronically ill, in an unfair way. A novel by Jersild (1978) caused another kind of upheaval in Sweden, in questioning the modern hospitals as places where mutual understanding between people had become impossible.

In Sweden a Public Health Act was implemented (Swedish Government Official Reports, SOU 1982: 763), which stipulated that the patient has the right to be involved in his own care and treatment. A consequence of this is that providers of health care need to understand the patients' perspective thoroughly. In other words, they need to understand the concepts of health and illness, and how these concepts are experienced by patients in their life situations.

One recent study on living with diabetes (Drummond and Mason 1990), referred to above, takes a 'patient centred' approach. These authors' task, as they saw it, was to 'improve clinicians' understanding of their patients' difficulties, thereby enabling them to tailor more appropriately the diabetic regimen to take account of the exigencies of 'real life'. One may assume that this 'tailoring' will occur as 'shared decision-making' or in 'dialogue', because, based on the analysis, these authors claim that: 'the 'weighing-up' that precedes the selection of a course of action, contains a rationale that can only be realized by understanding the setting of the patient in a context, and his or her understanding of that setting. (...) If such a view is accepted as legitimate, non-compliance cannot be interpreted as a failure by the patient to accord with the demands of a therapeutic regime whose function is to promote his or her well-being, but rather as the failure of the regime to accord accurately with the patient's own perception of his or her state of health" (Drummond and Mason 1990).

**Nursing care of diabetic patients**

The main type of health care needed by diabetic patients, in order to promote self-care, is information, backed up by help and support, based on an understanding of the meaning of being diabetic. Diabetic patients need to learn how to live. Henderson's often quoted definition of nursing is still relevant. She described the function of nursing as "assisting individuals (sick or well) with those activities contributing to health, or its recovery (or to a peaceful death) that they perform unaided when they have the necessary strength, will, or knowledge; nursing also helps

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individuals carry out prescribed therapy and to be independent of assistance as soon as possible" (Henderson 1978, p. 14).

The debate of what is nursing, and what makes nursing unique seems endless in academic nursing circles (Melia 1987). There have been a steady growth in 'models' and 'theories', and 'conceptual frameworks' in an attempt to develop a scientific basis for nursing practice (e.g. Orem 1980, Fawcett 1989). Diverse viewpoints coexist in the nursing literature. Although this has stimulated the debate, it has also kept alive a degree of dissonance between nursing theory and nursing practice (Firlit 1990), as nurses in practice often do not recognize these claims for a 'professional' independent nursing function.

Especially hospital-nursing is still subordinated medicine. Melia words it in this way:

"There is a problem for nursing if it is to lay a successful claim to 'profession'. The claim is essentially problematic because nursing work is not autonomous, by virtue of the fact that part of nursing's work is dictated by medicine. It also has to be said that nursing is too large and too heterogeneous a group to make any serious claim to professional status" (Melia 1987, p.166).

The stand-point that nursing theories, in a broad sense, are too abstract for application in practice is taken by Smith (1981) and Lundh, Söder and Waerness (1988). According to the latters: "they fail to say anything of interest about the social reality in which nursing takes place. - - The classless and genderless participants have been abstracted out of their social context"

Melia (1987) discusses two main segments of nursing, education and service. Based on nurse students' accounts of their world she says that: "It appears (...) that there may be a tension between those who theorize about nursing in this way and those who actually 'do nursing' " (p. 129).

However, in relation to diabetes patients, nurses seemingly play an important autonomous role in practice (Kinson and Nattrass 1984, p. 4) , with an emphasis on health-promoting care rather than on cure. Understanding patients' view is crucial when diabetes nurses 'do nursing'. When the present study was initiated I felt that nursing as a discipline would benefit from qualitative research with a focus on the diabetic patients' perspective. Their accounts of their experiences are predominantly "the concern of nurses" (Hockey 1982).

A qualitative paradigm
There are various qualitative approaches such as those rooted in anthropology or ethnomethodology that can all be viewed as modes of systematic inquiry concerned with understanding people and their actions
from their point of view. The purpose of enquiry in qualitative research is "to identify the properties existing in the real world and to gain a fuller understanding of what constitutes reality for the informants in a particular real-life setting. Thus the understanding that emerges from the research is the product of the interaction between the researcher and the phenomena under study" (Field and Morse 1985 p. 111). Using qualitative approaches in science, involves more than a consideration of data-collecting techniques. Qualitative approaches could therefore be conceptualized as a paradigm (Benoliel 1984). One explanation of a paradigm is "the entire constellation of beliefs, values, techniques, and so on shared by the members of a given community" (Kuhn 1970).

The "scientific" hypothesis-testing research method has been viewed as the only valid and reliable way to approach knowledge (Leininger 1985). This scientific method prevails as the dominant mode of discovery in medicine and other natural sciences. This method, however, has been questioned for its inadequacies and limitations in gaining a better understanding of people and their problems, for example in relation to illness. Many questions in nursing can not be answered by quantitative methods or by testing isolated aspects only (Medicinska Forskningsrådet 1982).

Koestler (1959 p. 548) wrote: "Post-Galilean science claimed to be a substitute for, or the legitimate successor of, religion; thus its failure to provide the basic answers produced not only intellectual frustration but spiritual starvation". Recently, the mechanistic world view has been further disputed by Capra (1982), who asks for "a new 'paradigm' - a new vision of reality, a fundamental change in our thoughts, perceptions, and values. The beginnings of this change, of the shift from the mechanistic to the holistic conception of reality, are already visible in all fields and are likely to dominate the present decade" (Capra 1982 p. xviii).

Lest this should sound too pompous, I have better state here that the present study does not have the ambition to give a totally "new vision of reality". Rather, its focus lies in the by and large taken-for-granted realities of the diabetic patients, from a holistic perspective. A more comprehensive understanding of the meaning of being a diabetic patient, which I will attempt to bring about, would hopefully be beneficial for health-care providers in their assistance of patients.
AIMS OF THE STUDY

My primary concern has been to develop a conceptual framework for an understanding of the management of diabetes from the perspective of type 1 diabetic patients.

Through informal interviews with type 1 insulin-dependent diabetic patients I wanted to learn the meaning of managing and coping with diabetes. Questions which have been at the back of my mind throughout the study were:

What can we learn from diabetic patients themselves, regarding their adaptation to the condition? What has actually helped them and what has caused difficulties, particularly with respect to the health care system, according to themselves? How is it that some seem to manage more efficiently than others, in terms of avoiding diabetes complications - again, according to themselves?

As a nurse teacher, at a time when nurses were looking for their identity and, especially in Sweden, were very concerned with trying to define their domain, I found it stimulating to work with a group of patients for whom nursing seemed to be so important. It was hoped that a contribution to the knowledge-base of nursing could be made through a study which used diabetic patients themselves as informants. Benoliel (1984) defines nursing science as "the systematic study of individual and group adaptations to health, illness, disability, and catastrophic change in relation to environmental influences and therapeutic actions". As the study lies within the realm of adaptation to illness in relation to 'therapeutic action', it hopefully adds to that body of knowledge, which predominantly is the 'concern of nurses' (Hockey 1982).

The aims of the study, thus, were:
- to shed some light on patients' experiences in the self-management of diabetes mellitus,
- to gain a deeper understanding of coping strategies used by diabetic patients facing long-term complications,
- to describe the patients' view of managing diabetes in their own terms and to juxtapose this with their accounts of how that differs from the view of the health care system.
"Grounded theory"

The interest to gain a deeper understanding of the management of diabetes from the patients' view led me to employ a qualitative interpretive research method.

Grounded theory method, as described by Glaser and Strauss (1967), offers a mode of generating theoretical concepts without preconceived hypothesis. Barney Glaser and Anselm Strauss were employed as sociologists by the Dean of the school of nursing when University of California San Francisco, as one of the first universities in United States, established a doctoral program in nursing in the early 1960s. (Stern and Allen 1984). Their research on dying resulted in the development of this theory-generating method, well-known for being a rigorous and elaborative account on a qualitative research approach. Jeanne Quint Benoliel was the first nurse who worked with a grounded theory study on dying (Stern and Allen 1984).

The task of the grounded theory researcher is to discover and conceptualize the essence of complex interactional processes. The central idea is that theory is generated from and grounded in data by a process of induction. The data are coded according to conceptual categories which are suggested by the data themselves (Melia 1987 p.188). Substantive theory is generated through continuous analyses of data, collected without preconceived hypotheses but guided by the emerging categories. The main feature of Glaser and Strauss' means of handling qualitative data is the 'constant comparative method', which does not insist upon universality or proof. As Melia (1987 p. 189) words it: "The intention is to generate and suggest, but not test hypothesis. The 'constant comparative method' as the name suggests, works by comparing each item of data with the categories which are, or have been developed, and seeing whether they fit. The data collection and analysis are carried out side by side and in this way the direction of the study is dictated by the emergent categories and theory".

A technique called 'theoretical sampling' is recommended in which the direction of further data collection is decided by the emergent categories. "This process produces cumulatively intense theoretical sensitivity into one's data as the integrative matrix of the emerging theory grows denser" (Glaser 1978 p. 36).
Grounded theories are guided "by the assumption that people do, in fact, order and make sense of their environment although their world may appear disordered or nonsensical to the observer" (Hutchinson 1986). People in similar situations experience shared meanings and behaviours and specific social psychological problems, which are "not necessarily articulated" (Hutchinson 1986). By interviewing or observing people in their natural context, by means of the constant comparative method, the researcher might be able to identify those processes which resolve the fundamental problems experienced by informants or participants in the study.

For the method adopted in this study I have used Glaser and Strauss' 'grounded theory method' as a model, although not followed that approach to the letter. Grahn (1987 p. 129) discusses this method in terms of being "stuck in a loop" because of its nature of being laborious, time-consuming, and hard to learn for beginners. Melia (1987 p. 189) states that "there is a fair amount of scope for interpretation within the Discovery of Grounded Theory". Melia uses as an example a sequence of 'theoretical sampling' from Glaser and Strauss' (1967 p. 77) book: "since each researcher is likely to encounter special conditions in his research, he will inevitably add to the discussion of theoretical sampling ... we would scarcely wish to limit this type of comparative analysis to what we can say about it, from either our own research or our knowledge of others' research. We have merely opened the topic."

Similar to Charmaz (1990), in her theory-generating study on chronic illness, I thought it would be productive to combine this method with a phenomenological approach, which aims to understand people's lived experience (Oiler 1982, Bogdan and Taylor 1975, Wagner 1973). Grounded theory is sometimes criticised for its "overly rationalized view of the individual, which a phenomenological perspective helps to correct" (Charmaz 1990).

Respondents

Some authors identify three phases of health and functioning in the 'diabetic life' (Isenberg and Barnett 1965, Hamburg and Inoff 1983, Jacobson and Hauser 1983, MacRae Holmes 1986). According to MacRae Holmes the first phase is the year after onset of the disease "with emotional upheaval attendant on diagnosis". The next phase, termed "the management phase" by Jacobson and Hauser (1983), is a time of relative well-being and functioning, which usually lasts several years. During this phase there are also periods of crisis due for example to the
developmental transitions or fluctuating self-image. The third phase begins when late complications occur and have to be coped with.

When this study was initiated it was considered helpful to use this sequence, and the selection of informants for the study was made with these three phases in mind. It was assumed that the respondents would represent a range of experience.

It has to be said here that apart from interviews with the respondents, which shaped the bulk of the data, there were other sources of 'data' which helped me to understand the problem under study. Stern (1982) discusses this point in the following manner: "the investigator comes to the scene with a lifetime of events in tow that are impossible to ignore. In truth, this involvement helps the investigator understand the problem under study". Glaser and Strauss (1967 p. 65) consider all kinds of information, from which the researcher gain an understanding of a category or its properties, 'slices of data'.

Noteworthy as additional data in the present study are notes from informal conversations with health care providers, other diabetic patients than 'the respondents' and relatives of diabetic patients. Mention should also be given to observational notes from a five days attendance of a 'diabetic camp' organized by the Swedish Diabetic Association (although I am not a diabetic patient myself). Information of this kind sometimes led to 'observational' or 'theoretical' notes using Schatzman and Strauss' (1973 p. 99) terminology (See paper II), but more often I have to admit, they led to implicit thoughts and ideas which later were involved in the cumulative process of 'generating theory'.

Hence, what I call 'the respondents' are those diabetic patients with whom I have had at least one interview of some length. Moreover, an appointment for that interview was made in advance, and at least some part of the interview took place privately between me and the respondent.

All respondents were out-patients at the Department of Internal Medicine in Umeå, in Northern part of Sweden.

A. The first selected patients had long diabetes duration and no long-term complications. Based on the assumption that these patients were successful in their management, it was hoped that they would provide useful information about managing diabetes, in the light of their relatively effective self-management. Antonovski(1987) used a similar approach when investigating how people had coped with difficulties in their life. He turned to various sources and asked for individual references to persons who had undergone severe trauma and were thought to be functioning remarkably well. In this study, however, one of the physicians at the Department, turned to the diabetes nurse's box of address cards, and picked out those patients he considered to be especially "well-adapted".
Table 1 General background data of the respondents, presented in chronological order of their first interview, and how they are represented in the different papers. 'In work' includes being housewife and student. 'Family' includes living together with a friend.

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These respondents had no signs of vascular complications in spite of long diabetes duration. Twenty-one respondents were selected in this way, of whom one refused to participate in the study. See paper 1 for a further description of these respondents. Another respondent was included to this group by me, at a later stage.

B. The second group of respondents was selected in a similar manner. However, three of the total group of 17 were later included by me. These 17 respondents were afflicted by diabetes complications, notably proliferative retinopathy with visual impairment. There were no refusals. Fourteen were interviewed at two occasions with an approximate 5-year interval. See paper III for a further description of these 14 respondents.

C. Ten newly diagnosed Type 1 diabetic patients, below the age of 40 years, were included in the study as the third group. They were consecutively diagnosed at the clinic during a ten-months period.

Table 2 is presented to give the reader an idea of the total number of diabetic patients in the health region of Umeå, from which the respondents were selected. These figures are taken from a study of the epidemiology of foot lesions in diabetic patients aged 15 to 50 years (Borssén et al. 1990). The number of diabetic patients in the health region of Umeå, with 118 500 inhabitants, was found to be 395, of which 298 (78%) had Type 1 diabetes. The proportion of diabetic complications, in this relatively young group of diabetic patients, was considerable.

Table 2. General background data of 298 Type 1 diabetic patients in Umeå. Nephropathy diagnosed with a urine test positive for protein when other causes had been excluded, Retinopathy diagnosed by an ophthalmologist, and Hypertension if on antihypertensive treatment (Lithner, 1990).

<table>
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<th>Duration(Mean)</th>
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<th>Retinopathy</th>
<th>Hypertension</th>
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<td>16,5yrs</td>
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<td>53%</td>
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Data-collection and concomitant analysis

Figure 1 illustrates the time-dimension in the data-collection and analysis processes toward a gradually more comprehensive pattern - 'the conceptual framework'.
FIGURE 1
The process of data-collection and analyses towards a comprehensive pattern of what it means to manage diabetes. The spiral could also be seen as a time-axis of about seven years, illustrating the temporality of this grounded-theory study.

= Interview with diabetic patient with long duration of diabetes. Twenty-two interviews with 21 respondents, 15 women and five men.

= Interview with diabetic patient with long-term complications. Thirty-two interviews with 17 respondents, 10 women and seven men.

= Interview with newly diagnosed diabetic patient. Twenty-one interviews with 10 respondents, three women and seven men.
Informal interviews

Informal interviews might allow the researcher to gain insights into the world of those being studied (Hutchinson 1986, Melia 1987 p. 190). All interviews were undertaken by me. The interviews, which in most cases took place in the respondents' homes, were held in an informal way and lasted between one and three hours. Sixty-seven of the total of 75 interviews were tape recorded and later transcribed. For a variety of reasons the use of the tape recorder was inappropriate for the remaining interviews and instead detailed notes were taken. Interviews focused on descriptions by the respondents of their experiences of managing diabetes. Although there was no intent to standardize interviews, a 'hidden agenda' as it is referred to by Melia (1987 p. 191), was used. Topics which were brought up spontaneously by respondents in early interviews were raised in subsequent interviews. In that way interviews fed into each other in scope and depth.

Although the intention was to talk to all the respondents in privacy, there were occasions when spouses or children or, at one occasion, parents were present at interviews. Instead of turning them out, I seized the opportunity to involve them in the conversation. Their contribution helped me to understand the problems experienced by the respondents. That was both in a direct way - when I gained a deeper understanding because of what they said, and in an indirect way when for example it became obvious during the course of the interview that wife and husband never had talked about the fearfulness connected to one of them having diabetes.

There were, of course, differences between interviews because respondents had their particular problems. In that way interviews with respondents with severe complications naturally dealt with their specific problems. Thus, they explored the respondents' coping-strategies to a large extent. Interviews with newly diagnosed respondents covered the personal meaning of 'becoming diabetic' and 'learning to manage diabetes' more fully than interviews with respondents who had long diabetes duration.

The period following the onset of the condition was discussed at some length with all the respondents. The question whether, and in what ways, the health care system had been helpful or had caused difficulties for the respondents' ability to manage was another topic that was brought up in interviews with all respondents.

The interviews in this study were conducted in a spirit of curiosity as well as respect for the respondents and for the information given. Stern and Allen (1984) evokes the idea that grounded theory method and the process of nursing are intricately linked together. There are a constant
comparison of collected and coded data, hypothesis generation, and collection of new data to verify or reject hypotheses involved in both processes. However, it would not be possible to gain an understanding of the patient's or the respondent's lived experience if only keeping to fact finding. The nurse's or researcher's ability to make the patient or respondent to feel respected, and accepted in the encounter is influenced by factors like genuine interest and communication skills (Davis 1981, Davis and Ternulf Nyhlin 1981 and 1982).

Ethical considerations
I have chosen to denote some of the issues inherent in the data-collection and analysis phase under this topic to emphasize the continuous choices which had to be made. Clearly, as I see methodological choices, they are often ethical in nature. They have to do with an awareness that different kinds of power exist in the relationship between researcher and respondent (Thompson et al. 1988). Also between researcher and health care providers there are inherent powers in the relationships, because the researcher receives personal intimate information from patients. This information must be handled with care not to cause damage to a 'third person' (Johansson 1974).

Thus, although respondents were encouraged to speak freely, they were not unduly pressed to talk about matters which they were reluctant to discuss. Delicate questions or issues liable to cause a break in relationships were not probed for methodological reasons only. In that way 'ethical considerations' sometimes determined the direction of the interview.

Validity and reliability.
In the process of gaining consent the potential respondents had been assured of confidentiality. The first interviews, with the "well-adapted" respondents, were re-coded and re-sorted in collaboration with one of the co-writers (Norberg), prior to the writing of paper I. She could not identify the respondents. This 'peer examination' (Field and Morse 1985 p. 121) of the data was made to see if the same preliminary categories, as found by me at earlier stages, could be identified (See paper I). By and large, that was the case.

The promise of confidentiality, however, resulted in the rest of the analysis being restricted to me - apart from the translation assistants, who stood outside the health care system and the research. Field and Morse (1985 p. 121) advocates another person to 'check' the interpretations in an effort to increase reliability and validity. On the other hand, Glaser and Strauss (1967 p. 225), emphasizing the 'credibility' of grounded theory, says that the researcher 'knows what he knows'. Also, because he has been living with his work for many months he 'knows that he knows'. In other
words, the researcher must trust his analysis. That does not mean that his analysis is the only plausible one that could be based on his data (Glaser and Strauss 1967 p. 225). As is the case of qualitative research in general, grounded theory is not replicable. Categories evolve in the interaction between researcher and respondents, or as Benoliel (1970) suggests, in a process of negotiation.

**DATA ANALYSIS, FINDINGS AND GENERAL DISCUSSION**

The researchers' "school of thought" is mentioned to provide the conceptual roots for the categories to grow (Charmaz 1990). In my case most of these "thoughts" have emerged during the course of the research. However, I acknowledge with gratitude some of the notions I already had come across when the study was first initiated, and which shaped the style of interviewing and, to some extent, the analysis. I had the idea that the diabetic patients would react to their circumstances, as they were interpreted by them, and that they would negotiate their role and determine their actions accordingly. Later I learned that this view was in line with a social psychological perspective named "symbolic interactionism" (Blumer 1969), on which grounded theory method is based (See paper II). Symbolic interactionism holds the view that "humans act and interact on the basis of symbols that have meaning and value for the actors. Examples of symbols include words for an object rather than the object itself, body language that communicates messages to others with or without words" (Stern and Allen 1984). This view derives from a classic notion that our ideas about self, especially our self-esteem, are influenced by the valuing of ourselves by others (Asplund 1967), expressed beautifully by Goethe (Eckermann 1987). There were thoughts like these in combination with a (vague) political awareness that people might be objected to inherent power in relationships due to social structural barriers (Freire 1972, Hernes 1975 p. 186, Gardell et al. 1979), which formed the basis for the emergence from data of the notion of a "hidden health care plan" inherent in the health care system, discussed in paper I.

Glaser and Strauss (1967 p. 31) say with reference to what kind of theory might be generated in grounded theory: "A grounded theory can be presented either as a well-codified set of propositions or in a running theoretical discussion, using conceptual categories and their properties. -- The form in which a theory is presented does not make it a theory; it is a theory because it explains or predicts something".
Although I have not made any promises of presenting a 'theory', it might be relevant here to present Glaser and Strauss' (1967 p. 32) view of theory as process. Thus, theory as process is "theory as an ever-developing entity, not as a perfected product. --Theory as process, we believe, renders quite well the reality of social interaction and its structural context".

Birchner (1986) defines conceptual frameworks as "loose aggregates of broad concepts". The presentation here is intended to correspond to that definition. The rather cautious approach, used in handling the data and in the analysis, derives from my perception of the limitations of the study. Indeed, the process of generating theory has been in my mind throughout. There has been a cumulative approach in that I have used ideas sprung from analysis of the data, in subsequent interviews, which is the idea inherent in Glaser and Strauss' 'theoretical sampling' (Glaser and Strauss 1967 p. 45-77). However, I have not followed the issue of 'theoretical sampling', which is the 'hallmark' of this theory-generating method, to the letter.

Walking a fine line
Walking a fine line was found to be the core category which explained managing diabetes from the perspective of diabetic patients themselves, or seemed to sum up "what is going on in the data" to quote Glaser (1978 p.94). One respondent said for example:

"There is a narrow border-line between keeping hale and healthy and being extremely run down".

After having done several interviews I discovered that the diabetic patients' unarticulated problem was one of 'keeping managing' and not 'falling below par'. This problem of 'managing' initiates the basic social psychological process of 'walking a fine line'.

If a diabetic patient is unable to 'walk a fine line' he or she fails in the self-management of the condition and is under risk of being afflicted with complications, both acute and long-term complications.

The process of diabetes self-management has several interrelated aspects:

Walking a fine line
a. Managing oneself
   -physically
   -emotionally
b. Managing the health care system
c. Social background factors

The first aspect 'Managing oneself' covers all those points which are mentioned in general textbooks on diabetes, perhaps with an emphasis on
the emotional management. That is the patient's balancing of "not only medication, meal plans, and exercise, but also stress" as MacRaeHolmes (1986) words it.

'Managing the health care system' seems to be incredibly important for diabetic patients and has a great influence on the whole balancing act (Paper V). Clearly, the contacts between the health care system and the patients are crucial also for the patients' abilities to adapt - perhaps even more pronounced when the patient is afflicted with long-term complications. Respondents felt that they had to manage the health care system in order to get the best possible and most appropriate treatment or care. They also, more or less consciously had to assure themselves that this care was in line with their own strategies for managing in their every day life.

Social background factors such as family-life, work-life and education affect possibilities to manage the balance act.

**Figure 2** Walking a fine line.

Interviews revealed that a continuum of strategies and attitudes, considering the self-management of diabetes (or the adaptation to diabetes) exists.

At one end of this continuum is the category "Mastering life", where the adaptation includes people's whole life-style.

At the other end of the continuum is the category "Evading the problem of managing". The diabetic patient's position on this continuum is, to a great extent, related to how he succeeds in his "managing the health care system", as well as social background factors are important.
Walking a fine line may not be the only process of theoretical importance in managing diabetes. However, it does elucidate much of the behavioural variation in the data. It captures the patient's need to balance his emotional and physiological state, as well as his interactions with the health care system. Patients who manage the balancing act may enjoy good health, but they are "walking a fine line" between maintaining this state and falling below par (Fig. 2).

A central feature of the respondents' accounts of managing their diabetes was the division between their view of the every-day management of the condition and the expectations, as they saw them, from the health care system. Divisions with regard to these two 'voices' - the voice of the lifeworld and the voice of medicine - have been illuminated in the literature (e.g. Mishler 1984, Sätterlund Larsson 1989)

However, these two different standpoints do not have to be mutually exclusive (Billig et al. 1988) Basically, there were no substantial differences between the diabetic patients themselves and the health care system in the notion of a "good efficient regime" for the management of diabetes (See paper V). Involvement of patients in their own care are wanted of both parts, for example. Patients and health care providers alike may have the same view, but misunderstandings occur on both parts. The health care system might not recognize when the patient needs help in his total life situation or when he needs plain advice on a medical problem. Also, the patient's messages might not be clearly spoken, because

- patients have to be carefully balancing their relations with the health care system, and
- patients may be ambiguous in their presentation of themselves.

The diabetic patient gets a view of how the health care system is structured and its demands of the patient. If he plays according to these preset rules he will however be confused, as there is also a hidden health care plan. The patient who eventually learns to manage the health care system as to get the best out of it, is either able to look through this facade or he might refuse to act in the play and merely makes demands himself, whenever the need arises. This might be frustrating for the health care providers. Demanding patients are often considered as bothersome.

Indeed, the conflict experienced by patients between
- the requirement to be involved in their own care, and
- the concomitant dependency on the health care system,
should be understood as the failure of the system to meet the patient in a dialogue, and not as the failure of the patient.
While from the patient's point of view the problem of a hidden health care plan becomes a reality, it is not recognized or discussed within the health care system. As long as this state remains an actual overall improvement as to the meeting of patients' needs seems virtually impossible.

The following presentation is structured under the following sub-headings as to illustrate the discussion above:

- Managing oneself "physically"
- Managing oneself "emotionally"
- Mastering life
- Evading the problem of managing
- Managing the health care system

Managing oneself 'physically'.
This category refers to the patients need to learn to calculate the different factors: the amount of food, insulin, exercise, in order to maintain the "metabolic balance".

Learning proceeds from counting and measuring everything to more "proficient" ways, where for example recognising body-signals are important. Self-knowledge is essential for this aspect of the balance (See paper I).

Not only newly diagnosed respondents, but also respondents with long-standing diabetes made regular blood-sugar tests at home. That possibility as well as the recent development towards taking insulin several times a day, had meant a great deal for most respondents by giving them more freedom. Many of the respondents with long diabetes duration had occasionally taken extra doses of insulin also in earlier days, but then with a sense of guilt.

Managing oneself 'emotionally'.
The connection between emotional and physiological well-being, for instance with regard to the blood-sugar level and hypertension, was well known and recognized by respondents. Especially respondents with complications had difficulties to bear stress and stressful situations, which was even seen to be "what it all is about". The matter of uncertainty, when afflicted with complications, constituted an impeding factor with regard to managing emotionally. The risk of being subjected to unpredictable demands was avoided by respondents, as a coping-strategy, as described in paper III.

When possible, daily activities were carefully planned, and in doing so, respondents could feel that they managed to live an independent life. For example, a category which emerged early on, and which is described
more fully in paper I, was: "Being dependently independent". Also interactions with others were planned, in order to avoid frustration and anger. That applies to interactions with the health care system as well, as is further discussed in paper V.

There was an awareness among respondents with long duration that diabetes would most likely shorten their lives:

"I am not counting on growing old. Maybe I have another ten years to live."

The notion that "The days are numbered" - a category described in paper I, sometimes caused anxiety. Respondents feared vicious circles in which they lost foothold or control. The feeling of meaninglessness or anxiety could cause respondents not to adhere - a matter which they were fully aware of and thus tried to avoid. It is difficult to "keep going" and sustain motivation when being depressed. Not managing so well, in turn, could cause a feeling of failure.

Respondents facing long-term complications had to 'manage emotionally' and learn to cope with uncertainty, caused by the changeable situation and by organizational factors of the health care system, as suggested in paper III. Respondents' adaptability, through learning new manners of 'keeping going' and 'making sense' of their total situation were impressive.

Mastering life.

Hence, to manage or to master one's diabetes well, means always keeping the condition in mind without being stressed by it (paper IV). It means a more or less conscious juggling with different factors, directly or indirectly affecting the general well-being. It means a balancing in which one false step might be dangerous. It is not possible to walk a tight rope watching only one's feet! Likewise, it is not possible in the long run to manage diabetes watching only the blood sugar level. The entire situation must be balanced by the diabetic patient, including projection into the future, but without being stressed by it. Respondents emphasized the importance of a sense of coherence which gives meaning and is possible to grasp, a notion also discussed by Antonovski (1979). The following account may illustrate that:

"You have to hold on to a consistent line through life"

The diabetic patient must, in other words, be something of a master in life. There is an interplay between many different factors, such as physical and emotional equilibrium. However, the diabetic patient who wants to be successful in managing his diabetes has to learn to trust himself and his own judgement:

"...one should not rely on others. You mustn't let it go that far. That is important. The feeling of being wrapped in cotton wool is terribly dangerous just as feeling unattended is. One should never allow oneself to get into that situation. One should
try to get others to respect the expectations one has of oneself and them. Not always feel sorry for yourself. That is also required, of course. Not only for diabetics."

The "well-adapted" diabetic patient lives with an awareness of his own possibility to act in accordance with what is believed to serve his own physical and emotional well-being. The anxiety created by the consciousness of this necessity has also a helpful element. It tends to lead to reflection and action, or in Kierkegaard's words: "For him dread becomes a serviceable spirit which against its will leads him whither he would go." (Kierkegaard, transl. by Lowrie 1944)

Adaptation was not static for respondents in this phase, but was an ever changing situation. Interviews revealed that when accepting and understanding that new learning situations will continue to arise it seems possible to fully "adapt".

However, the balance can become more complicated after long duration of diabetes. Also those who have considered themselves as mastering their diabetes in earlier days, and have been trying to extend their knowledge continuously, may feel confused:

"I don't bother so much to find the reasons any longer, instead I just adapt to the situation."

There are frequent occasions when old well-known methods of controlling the metabolic state or to sustain a degree of health are no longer working.

"One has had this diabetes so long now, but it feels as though one knows less and less about it. Sometimes one gets terribly thirsty without knowing why."

It is then important not to worry unnecessarily and to keep up the motivation, that in spite of everything it is worthwhile to try to look after oneself and not be discouraged.

The influence of social background factors emerged as, in turn, affecting respondents' capability to manage oneself and to manage the health care system. To manage diabetes efficiently seemed to be equal to master one's entire life. None of the respondents had severe social problems. Whether that is a sign of their attempt to organize their social environment as they organize their self-management can not be answered. It would however, be a matter of interest for a further study.

_Evading the problem of managing_
Most respondents had at times not taken their diabetes seriously into account. Among reasons for evading the problem of managing, were difficulties in accepting the disease leading to repression. Also, respondents said that they simply had not understood the complex
demands set by the condition. Other reasons were expectations from family or partner, as they were interpreted by respondents. If for example a relationship is based on the implicit assumption that having diabetes does not make any difference for everyday life, it may be difficult to pursue an arduous self-care regime. In our society health is important for one's self-esteem. The person who is afflicted with a chronic disease like diabetes might feel they can not live up to that standard set by society. Often respondents with long standing diabetes had concealed their condition, especially in earlier years.

"It is an illness which I don't advertise if I don't have to."

It might be a very high price to pay, with regard to self-image and confidence in relation to others, in always choosing the "appropriate" way of managing. In retrospect, respondents could see how they occasionally had chosen "the easy way out". To defend that way and to ease anxiety they had used as examples others, who had managed without long-term complications, in spite of neglecting advice on their self-care. Some "research" findings presented in the media, were also used to avoid tackling a certain problem, for example giving up smoking.

"When you are a smoker you take in everything that claims that it is not so dangerous."

There was nevertheless pride in coping with the total situation among those who did not seem to acknowledge the problem of diabetes management.

The more difficult it becomes to be diabetic, the more it seems the diabetic patient must concentrate on the total life situation rather than merely on the daily management of the illness. For example, none of the respondents with complications expressed any anguish. They believed to have done their best, all things considered. Maybe there was - with some- a certain bitterness of the fact that the know-how of the health care personnel, from a holistic point of view, had not been better earlier. There was a belief that if being affected by diabetes now, instead of several years ago, all other things being equal, they would have had a better chance to learn and accept what it was all about. Health care providers' attitudes towards patients were regarded as more humanistic now compared with some decades ago.

Most of the respondents had experiences of having concealed their disease to get a job or in relation with others, especially during adolescence, or had cheated when they visited the hospital. They had searching thoughts now, of who they were and who they would have been were it not for the diabetes. "A cheat-work" one of the respondents described her life.
Managing the health care system
To get the best possible and most appropriate treatment or care, to meet their needs, respondents had to manage the health care system. Moreover, they more or less consciously had to assure themselves that this care was in line with their own strategies for managing.

To manage this "entire balancing act", manoeuvres for avoiding frustration and stress, caused by feelings of disappointments with the health care system, were used by some. One issue which emerged in interviews was for example the importance for respondents to be considered by health care personnel to be responsible and diligent with regard to self-care - to be a "good patient", and strategies connected to that (Paper V):

What is it that really keeps us going? Well, it is being liked. If that is the case, they can achieve anything. If I can show good test results and if I can cooperate, they like me. This allows you to put up with things which you would not stand for when you come home.

At the same time, respondents seemed to manage their diabetes at a level of compliance which they found beneficial, all things considered:

I don't adhere to the regime as a diabetic should. In that I don't keep to diabetic diet. And I smoke as well. It is a disaster, actually. But on the whole I try to keep every day in a fairly regular rhythm and alike. There are no great jumps hither and thither. Actually I don't think I mishandle myself really. In spite of not keeping to this diet.

In this belief: "I don't think I mishandle myself really", there seems to be a dichotomy in the respondents' way of handling the condition, and in how it "should be" handled, from a medical point of view.

Patients learn to adapt to expectations, as they interpret these, through a process described in the literature in terms of socialisation (Bond and Bond 1986, p. 197).

Two issues seem to confront each other in the field of diabetic care:

On the one hand health care providers are being made more aware of the importance of self-care and, therefore, the need to listen to the patient - the "voice of the lifeworld". The traditional manner of communicating medical advice - the "voice of medicine", is no longer unanimous. Although this is a long-desired wish by patients, it is at the same time less plain.

On the other hand, diabetes complications cause patients to become dependent on the health care system, a matter which in turn makes them cautious in their interaction with the health care system, not to be regarded as bothersome.

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One tentative hypothesis generated from patients' accounts - which, however, needs to be further elaborated and tested - is:

Diabetic patients who are viewed as "well-adapted" by the health care system, use strategies for handling their disease which are equal to "mastering their entire life". However, when patients who are afflicted with complications use similar strategies for managing their disease and life, they feel that these ways are not acknowledged by the health care system.

Respondents in this study had to adapt to limits within the health care system, set by unwritten rules, sometimes subtle and difficult to understand (Paper V).
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