Guided Self-Determination

a life skills approach developed in difficult Type 1 diabetes

Vibeke Zoffmann

PhD thesis
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Guided Self-Determination, a life skills approach developed in difficult Type 1 diabetes

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Preface

The quality of living is the quality of people managing their experiences together towards common purposes.

L. Thomas Hopkins 1954
Outline of this thesis and the PhD project

This thesis is based on the project ‘Guided Self-Determination – A life skills approach developed in difficult diabetes care’ conducted at Aarhus University Hospital in Denmark from 1996 to 2004.

The empirical and theoretical background for method innovation in chronic care and the reason for selecting diabetes are described in Chapter 1. The aim of the PhD study is presented in the first part of Chapter 2 provides an overview of design and methods.

Three inter-related grounded theory studies based on data from 1996 to 1997 formed the basis for developing the Guided Self-Determination approach. A ‘Life versus disease conflict’ is presented in Chapter 3, ‘Relational potential for change’ is presented in Chapter 4 and a ‘Model of person-specific reflection’ is presented in Chapter 5. Chapters 3, 4 and 5 were written as independent articles for publication.

Chapter 6 details the process of advancing these qualitative findings into intervention by developing Guided Self-Determination (GSD) in clinical practice in 1998-2000. It also presents the qualitative results of testing the clinical significance of GSD in a one-to-one setting. The refinement and adjustment of GSD to group training and transition from qualitative to quantitative evaluation are presented at the end of Chapter 6. The applicability and the statistical significance of Guided Self-Determination in group training was tested in a randomised controlled study in 2001-2003. This study is presented in Chapter 7 written as an independent article for publication.

Chapters 8 and 9 offer a comprehensive and more general discussion of the methods used and the results presented in the thesis. A conclusion and additional perspectives to the research question posed are provided in Chapter 10 and 11.

English and Danish summaries are provided in Chapter 12 and 13 and the references used throughout the thesis are listed (pp. 184 -191). Appendices provide interview guides, parameters, an overview of the measures applied, questionnaires in English and Danish, work sheets and other materials used in Guided Self-Determination as well as information on the participants in the study.
This thesis is based on the following papers


II. Zoffmann V, Kirkevold M: Relational potential for change. Types of relationships in difficult problem solving. Ready for publication.


IV. Zoffmann V, Lauritzen T: Guided Self-Determination improves A1C and self-management of Type 1 diabetes in randomised controlled trial. Ready for publication.
Motivation
This thesis is based on studies carried out in Denmark at Aarhus University Hospital between 1996 and 2004. The idea for the project came in 1985 during my studies at Denmark’s High School for Nurses in Aarhus. On seeing Imogene King’s model of interactive problem solving, I was aware that some sort of idea had occurred to me. Not until 1996, however, did the idea result in empirical research.

Acknowledgements
The study would never have succeeded, had it not been for the tremendous support I have received from my nursing and research colleagues, research funds and advisers.

I am greatly indebted to my three advisers, Professor Steen Wackerhausen, Associate Professor Ingegerd Harder and Professor Torsten Lauritzen. You have been a scientifically strong and enthusiastic team, you have believed in me and have encouraged me through the good times and the bad during the project. I am also greatly indebted to Professor Marit Kirkevold for fruitful discussions and advice in the final part of the study.

The administrators at the Department of Endocrinology have shown me confidence, believed in the project idea and supported me in many ways. The study included an intensive training program for diabetes nurses. I am truly grateful to the nurses at Aarhus University Hospital who participated in the study and were ready to change their approach to problem solving and participate in the training program. During this process the following nurses offered their assessments in developing and testing Guided Self-Determination: Anne Marie Risager, Birtha Hansen, Dorthe Møller, Heidi Nielsen, Jeanette Lagoni, Solveig Sørensen, Tove Amby and Åse Jensen. Nursing leaders Birthe Mors, Else Krüger, Jytte Løkke, Jane Kjeldsen and Guri Engmark provided unfailing support in prioritising the project over many years.

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Skovlund from Novo Nordisk gave in finding a way through the jungle of diabetes scales. Moreover I will like to thank Kirsten Lomborg for many inspiring discussions about qualitative method.

I owe my sincere thanks to the flourishing research team at the Institute and Research Unit of General Practice at Aarhus University who provided me with an office for the three years of the study. I thank my office colleagues Jette Kolding Kristensen and Helle Therkildsen for fruitful discussions. I appreciate the help I have received from secretaries Eva Therkildsen, Eva Højmark and Anni Michelsen and the effective computer assistance provided by Bjarne Benner and Lars Olesen.

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Last but not least I would like to thank all the patients who participated in the project. It was made for you - and without you it would never have been made.
### Abbreviations

<table>
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<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>A1C</td>
<td>Haemoglobin A 1 c = HbA1c</td>
</tr>
<tr>
<td>BG</td>
<td>Blood Glucoses</td>
</tr>
<tr>
<td>BSD</td>
<td>Balanced Self-Determinism</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence Interval (95% in this thesis)</td>
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<tr>
<td>GSD</td>
<td>Guided Self-Determination</td>
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<tr>
<td>GSD-GT</td>
<td>Guided Self-Determination in Group Training</td>
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<tr>
<td>HCCQ</td>
<td>Health Care Climate Questionnaire</td>
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<tr>
<td>HbA1c</td>
<td>Haemoglobin A 1 c</td>
</tr>
<tr>
<td>PAID</td>
<td>Problem Areas In Diabetes</td>
</tr>
<tr>
<td>PCD</td>
<td>Perceived Competence in Diabetes</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomized Controlled Trial</td>
</tr>
<tr>
<td>SE</td>
<td>Standard Error</td>
</tr>
<tr>
<td>TSRQ</td>
<td>Treatment Self Regulation Questionnaire</td>
</tr>
<tr>
<td>WS</td>
<td>Work sheets</td>
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<tr>
<td>SMBG</td>
<td>Self Measured Blood Glucoses</td>
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<tr>
<td><strong>Active listening</strong></td>
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<tr>
<td><strong>Amotivated reasons to act</strong></td>
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<tr>
<td><strong>Autonomous reasons to act</strong></td>
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<tr>
<td><strong>Balanced Self-Determinism</strong></td>
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<tr>
<td><strong>Controlled reasons to act</strong></td>
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<tr>
<td><strong>Coping</strong></td>
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<tr>
<td><strong>Empowerment</strong></td>
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<td><strong>Grounded theory</strong></td>
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<tr>
<td><strong>Guided Self-Determination</strong></td>
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<td>-----------------------------</td>
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<tr>
<td><strong>Health Care Climate Questionnaire (HCCQ)</strong></td>
</tr>
<tr>
<td><strong>Haemoglobin A1c (HbA1c)</strong></td>
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<tr>
<td><strong>I-you-sorted communication</strong></td>
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<tr>
<td><strong>I-you-sorted relationship</strong></td>
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<tr>
<td><strong>Life skills</strong></td>
</tr>
<tr>
<td><strong>Method</strong></td>
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Model of dynamic judgment building

An ideal-typical model that reflects assessment in groups. Assessment is described as a process of rhythm enacted between three sets of poles: between two major poles cognition and choice and between two sets of included poles: facts and thoughts included in cognition and goals and routes included in choice.

Mirroring

One person mirrors another person’s behavior by sharing with the person what they have observed concerning this behavior (without sharing their interpretation of the behavior).

Other-determined behaviour

An individual’s behaviour is other determined when they passively look to someone else (or to some institution) to make decisions on their behalf. Typically, other-determined behaviour leaves a person feeling hurt, anxious and inhibited, in which case their sense of personal worth is diminished.

Problem Areas In Diabetes (PAID)

A questionnaire widely used as a measure of currently experienced diabetes-related emotional distress. The scale consists of 20 items and scaled answers to an overall question: Which of the following diabetes issues are currently a problem for you? Items are scored on a five-point scale from 0 (not a problem) to 4 (a serious problem). Subscale scores and total scores were totalled and transformed to 0-100, with higher scores indicating a higher level of distress.

Perceived Competence in Diabetes (PCD)

A questionnaire applied in a 3-item version used as a measure of the degree of competence perceived by patients in terms of diabetes management. The items were scored from 1 (strongly disagree) to 7 (strongly agree).

Selfish-Determined behaviour.

An individual’s behaviour is selfish-determined when they aggressively achieve their own goals at the expense of others. Typically selfish-determined behaviour produces a residual sense of guilt, in which case the sense of personal worth is diminished.

Self-concordance

Self-concordance to individual goal-systems is the degree to which stated goals express an individual’s enduring interests and values.

Self-determination

Self-determination is a quality of human functioning that involves the
experience of choice, in other words, the experience of an internal perceived locus of causality. It is the capacity to choose and have those choices be the determinants of one’s actions.

| Treatment Self Regulation (TSRQ) | Questionnaire applied in a 21-item version consisting of three subscales measuring whether the patients’ reasons for taking diabetes medication, checking glucoses, following diet and exercising regularly were (I) autonomous, (II) controlled or (III) a-motivated. The items were scored in the same way as the HCCQ and scores were averaged on each subscale. |
| Values clarification | Is a reply or a question which encourages another person to reappraise their values. In this way the person is encouraged to choose consciously, confirm a choice or act consistently with a choice. |
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Chapter 1

General introduction
1.1. IDEA

The central idea of this thesis is to study the need and provide solutions for method innovation in relational problem solving. The decision to select diabetes as a context for the study was therefore only secondary. It may already be worth noting in this introduction that the reason for this decision was not that problem solving for diabetes was especially inadequate but rather the opposite. I hypothesised that optimal insight into the refined apparatus needed for a method of relational problem solving would be achieved by studying the most difficult and complex relational problem solving in an advanced area. Diabetes care was considered to be just such an advanced area, having for a long time been known for employing quite an advanced view of patient involvement. The most difficult and complex relational problem solving in this area was considered to take place in interactions between professionals and diabetes patients with poor glycaemic control. A method developed from such an area might provide advanced apparatus, which in principle might be transferred to other contexts.

A considerable percentage of people living with diabetes do not benefit from traditional interventions when trying to reach a level of glycaemic control optimal for preventing disabling complications \(^1\text{-}^4\). According to local research and laboratory based data from the county of Aarhus, the second biggest city in Denmark, about 40% of people with Type 2 diabetes and about 50% of people with Type 1 diabetes live with HbA1c \(\geq 8.0\%\) (ref. 5.1 – 6.2%) \(^5\). If the same proportion holds throughout Denmark, which has a population of about 5.5 million people, poor glycaemic control would affect 52,000 of the 130,000 people living with Type 2 diabetes and 10,000 of the 20,000 people living with Type 1 diabetes. These figures are used in the current study as an indication that innovations in diabetes management strategies for patients with persistent poor glycaemic control are needed and that the efficacy of relational problem solving between patients and professionals has to be considered.

Diabetes research has for a long time argued that relational problem solving between patients and professionals should consider the fact that patients are the real problem solvers in their lives with the disease. A comprehensive range of formal theories such as empowerment\(^6\text{-}^8\), coping skills training\(^9,10,10,11\), self-care\(^12,13\) and self-determination\(^14\) support this idea. Though research has on the one hand documented that, for instance, empowerment can be learnt by professionals\(^6\) and has a positive effect on diabetes self-management\(^15\) it has on the other hand also revealed serious problems in implementing such approaches in clinical practice\(^16,17\). Even patients with good glycaemic control thought that their problem solving skills were undervalued by professionals...
despite the fact that these same professionals had invited them to co-operate and stated that they supported the idea of empowerment\textsuperscript{18,19}.

This thesis follows the idea that inappropriate methods applied in relational problem solving play a considerable role in the failure to implement empowerment in clinical practice. I even hypothesise that diagnostic methods in nursing and medicine may be counterproductive to autonomy support. These methods are often inconsistent with autonomy support and there is a need for a new apparatus of methods to overcome the barriers that currently exist in relational problem solving between patients and professionals.

I further hypothesise that influencing the attitudes and theories of professionals will be an almost entirely wasted effort for as long as clinical practice does not provide more appropriate methods for relational problem solving. Establishing a basis for and implementing an innovation of methods in relational problem solving has thus become the main purpose of the thesis.

My assumptions about deficiencies in methods prior to the study can be expressed under five headings: provider dominance, exclusively rationally oriented, mono disciplinary character, linear thinking and poor applicability in busy clinical practice. Firstly, provider dominance was revealed in the very terms used such as ‘nursing or medical diagnostic methods’, which expressed an assumption that professionals should be the problem solvers and a corresponding lack of potential for involving patients in assessment. The methods actually applied were in contrast to ideas of, and earlier research into, interactive problem solving\textsuperscript{20-22}. Secondly, it was ascertained that the methods were only expected to address the rational parts of problem solving and lacked the apparatus for handling power differences, difficult feelings and different points of view between patients and professionals. I thus hypothesised that professionals’ ability to clarify misunderstandings etc. was low and that they were not benefiting from, for example, knowledge developed in empirical research undertaken by for instance Orlando forty years ago\textsuperscript{21}. Thirdly, it was assumed that the mono-disciplinary character of the methods perpetuated parallel decision-making processes and thus prevented a synthesis of the diverse competences in the interdisciplinary team. This would in turn impede the realisation of ideas of interdisciplinary collaboration\textsuperscript{23,24}. Fourthly, the methods appeared to be an example of linear thinking in that they assumed that one stage should be followed by another. It was hypothesised that replacing methods conveying this kind of linear thinking with methods conveying more spontaneous, dynamic and creative reflection might enhance the quality of reflection in daily clinical practice\textsuperscript{25,26}. The fifth issue questioned was the methods’ apparatus for improving problem solving under the conditions of the limited time...
available in clinical practice. It was furthermore assumed that current methods in diabetes care advocated a compliance paradigm and were thus counter-productive in helping people develop self-management of chronic illnesses.

The thesis presumes that effective relational problem solving between patients and professionals requires methods that are consistent with empowerment and provide the apparatus for overcoming existing barriers in relational problem solving between patients and professionals. Furthermore, it is presumed that failed problem solving in difficult diabetes care is partly due to methods which are inconsistent with empowerment and lack the necessary apparatus for overcoming barriers.

**The central hypothesis of this thesis is:**

1) The effectiveness of relational problem solving to develop patient self-management in difficult diabetes care will increase if current methods are replaced by methods known to be consistent with empowerment and having the apparatus to overcome barriers in the context of difficult diabetes care.

### 1.2. Aims

The overall purpose of the study was to develop and test a method for relational problem solving which is consistent with empowerment and includes the necessary apparatus for overcoming barriers to developing self-management in difficult diabetes care.

The aims of this thesis are:

1. To present grounded theories derived from patient-provider interactions in difficult diabetes care
2. To detail Guided Self-Determination and describe the participatory process of developing the method
3. To illustrate how the impact of Guided Self-Determination was determined qualitatively in difficult diabetes care
4. To present the effects of Guided Self-Determination on the self-management of diabetes including glucose control
5. To discuss the results and their consequences for clinical practice and future research
1.3. THEORETICAL FRAMEWORK

Theoretical inspiration prior to the study came primarily from philosophy and humanistic psychology\textsuperscript{27-33} as well as from nursing theory\textsuperscript{20;21;34;35}. The theoretical framework, however, developed during the course of literature studies related to clinical research\textsuperscript{36} and the grounded theory studies in phase 1.

The method innovation resulting in the development of Guided Self-Determination (GSD), was formed from a synthesis of the grounded theory analysis in the first part of the study and three formal theories: 1) Life skills theory\textsuperscript{37;38} as an overall theoretical framework (closely related to the philosophy of empowerment and motivational theory of self-determination), 2) An ideal-typical model called the ‘model of dynamic judgment building’\textsuperscript{25} as a problem solving and decision-making model,\textsuperscript{26} and 3) Trans-theoretical stages of change theory\textsuperscript{39} transformed into a clinically applicable screening instrument for identifying the readiness of Type 1 diabetes patients to change.

The origin of these theories and the reasons for combining them with the grounded theories will be outlined in the following sections. Specific connections identified in the grounded theory studies will be explained in Chapters 3-6. The development of instruments in the form of work sheets are described in Chapter 6, pp 96-101.

1.3.1. Life skills training

A health promotion glossary put me on the track of life skills training, which appeared to be a rather neglected dimension of diabetes care according to the initial part of my study. The glossary concluded that developing life skills in individuals was an important goal for health promotion, defining such skills as follows:

\textit{“Those personal, social, cognitive and physical skills which enable people to control and direct their lives, and to develop the capacity to live with and produce change in their environment.”}\textsuperscript{40} p.121.

Examples of individual life skills might include “problem identification, problem solving, decision making and conflict resolution”\textsuperscript{40}. “Posing of problems” is also mentioned as an example of life skills\textsuperscript{41}.

A conceptual approach to life skills was presented in 1984 in a dissertation by Brook\textsuperscript{37}. A combined literature and Delphi survey providing a life skills taxonomy was developed through the
use of a three-round Delphi survey. Brook’s exhaustive review of the literature of human development theory and research yielded a pool of life skills descriptors and a group of 191 experts who were formed into three panels to respond to the descriptors appropriate for the three major life periods of childhood, adolescence and adulthood. The result of the study was a taxonomy consisting of 305 life skills descriptors classified into eight categories of widely varying scope and detail: Interpersonal Communication (IPC), Human Relation Skills (HRS), Problem-Solving (PS), Decision-Making Skills (DMS), Physical Fitness (PF), Health Maintenance Skills (HMS), Identity Development (ID) and Purpose-In-Life-Skills (PILS).

Another conceptual framework for a life skills program was written by Mullen in 1985 on the basis of more than a decade of experience from the Saskatchewan New Start program in Prince Albert, Canada. The first life skills course at Saskatchewan was developed in 1968 against the background of difficulties in expanding business and industry into impoverished areas of Canada during the post-war period. Skilled personnel too often had to be brought in from outside because no local people had the required qualifications. Job training and upgrading courses proved to be an inadequate solution because dropout rates before completion of training were high.

“Life skills are defined as problem solving behaviours used in the management of personal affairs. They apply to five areas of life responsibility: Self, Family, Leisure, Community, Job.”

According to Mullen, life skills students often had distorted views of themselves, exaggerating their lack of skills and showing little understanding of their abilities relative to other people. They were apprehensive in non-threatening situations. In particular, they allowed other people to dominate them. Students were often unable to work out marital quarrels in satisfactory ways. Some lacked the skills needed to identify problems, to recognize and organize relevant information, to describe reasonable courses of action and to foresee the consequences. They often failed to act on a rationally identified course of action, submitting rather to actions based on emotion or authority. Often they did not benefit from experience since they did not evaluate the results of their actions once taken and displayed fatalistic rationalizations of the consequences. They lacked the self-confidence to develop their abilities and had low or often surprisingly unrealistic aspiration levels. Students lacked effective ways of seeking help from each other and from agencies. Long periods of unemployment or frequent job changes marked their work history. They
had ineffective interpersonal relationships and lacked basic communication skills; they did not use feedback effectively, often thinking of it as hurtful personal criticism.

Mullen describes how the content of life skills courses at Saskatchewan developed over four levels of discovery and growth through action research 38 pp.8-10. At the first level, training was planned with a strong emphasis on human relations and communication. At the second level training in problem solving was incorporated in order to respond to a deeper level at which needs were seen to lie. At the third level the concept of Balanced Self-Determinism was presented (BSD). At the fourth level a yet deeper need was identified: “The need to recognize one’s self to be of value – as valuable, basically, as every other person”.

The aim of life skills training was to develop a balanced self-determined person, solving problems creatively in everyday life and obtaining the development of a self-concept, which leads to the formation of a coherent image of oneself in interaction with others.

“Balanced Self-Determined individuals are able to exercise their rights without denying the rights of others. Other-Determined individuals passively look to someone else (or to some institution) to make decisions on their behalf. Selfish-Determined individuals aggressively achieve their own goals at the expense of others” 38 p.9.

Mullen states that Other-Determined behaviour typically leaves a person hurt, anxious and inhibited. Selfish-Determined behaviour produces a residue of guilt. Consequently she concludes that the sense of personal worth in both cases will be diminished. Mullen asserts that coaches for life skills courses, who study the BSD concept during their training period, are supposed to recognize its validity in their own experience, applying its principles in their personal lives and in life skills coaching. Though acknowledging that a life skills goal might not be realized during the relatively short duration of a training course, Mullen states that a spiralling process, which moves towards the achievement of Balanced Self-Determinism is at least initiated during training.

1.3.1.1. Related theories
Conceptual relationships exist between life skills theory and more established theories in diabetes care such as empowerment, self-care, self-determination, self-concordance, integration and coping skills. It can be argued that the life skills theory is the most comprehensive of these. As is clear
from the following definitions, there are particular overlaps between life skills and two of the other theories: empowerment and self-determination.

“The process of empowerment is the discovery and development of one’s inborn capacity to be responsible for one’s own life. People are empowered when they have enough knowledge to make rational decisions, control, resources to implement their decisions and experience to evaluate the effectiveness of their actions” 42 p.11.

Several studies related to empowerment in diabetes care have been conducted, especially at the Michigan Diabetes Research and Training Centre. Regarding empowerment as a philosophy, they have concentrated on attitudinal development of professionals 43,44 and less work has been done on furthering the methods applied during effect studies of empowerment used in groups 45.

Self-determination theory has been developed from empirical motivational research46.

“Self-determination is a quality of human functioning that involves the experience of choice, in other words, an internal perceived locus of causality”. “Self-determination is the capacity to choose and to have those choices be the determinants of one’s actions” 46 p. 39.

Self-determination distinguishes between three kinds of motivation for human action: 1) People acting on the basis of amotivation act in a half-hearted way and arebuffeted by forces beyond their control. They feel helpless with respect to these forces and are unable to control their behavior. 2) With controlled reasons to act, people experience initiating events as a pressure to perform or act in accordance with that pressure and do not experience a real sense of choice. Their functioning is to a great extent determined by controls in the environment or by internal controlling imperatives. Self-aggrandizement follows success while guilt and shame follow failure. 3) With autonomous reasons to act, people have an experience of choice and use the available information to make choices and to regulate themselves in the pursuit of self-selected goals.

One study in diabetes care has documented that the degree of autonomy support perceived by patients with Type 1 and 2 diabetes is a predictor of their improvement in glycaemic control one year later14. The ‘self-concordance’ of individuals’ goal-systems is the degree to which stated goals express an individual’s enduring interests and values. Self-concordant goal-setting is in line with self-determination but adds a value dimension to the understanding of people’s basis for
goal-setting. Studies among college students have concluded that people more easily attain and reap greater well-being from goals that have a substantial degree of autonomy. Life skills studies often apply creative methods in their approach. Life skills studies have been conducted over many years in psychiatry and a life skills scale has been developed and tested. The need for randomised controlled life skills studies has been stated. In diabetes care, however, life skills theory has hardly been applied. A MEDLINE search found only one study describing how a life skills curriculum was useful at summer camps for young people with Type 1 diabetes.

1.3.1.2. Life skills training as part of diabetes care

Outside diabetes, an increasing number of life skills studies have been conducted in the last decade, often with a preventive purpose such as the prevention of cigarette smoking, or in the care of different patient groups such as people with handicaps and the care of both young people and the elderly.

The development of life skills with diabetes was hypothesised to be a suitable goal for individual diabetes care. As they are comprehensive and stick to an overall and essential purpose, life skills may help us abandon a fragmented view of health care that easily loses its way in details with which patients are asked to comply without seeing their meaning. Life skills conceptualisation may meet the need expressed by Paterson for a revised conceptualisation in diabetes care that “acknowledges the uniqueness, fluidity and authoritative knowledge basis of the everyday self-care decisions of people with chronic illnesses”.

Helping people to develop life skills with diabetes was recognised as the desired goal for Guided Self-Determination. The project thus assumes that the diabetes teams have two interrelated tasks: 1) To diagnose and treat diabetes as a medical disease including the prevention, delay and treatment of its complications and 2) To help people to continue to develop life skills with diabetes throughout their lives. In the current thesis I have regarded empowerment as being the philosophy, Guided Self-Determination as being the method and life skills as being the goal (Figure 1.1).
1.3.2. The model of dynamic judgment building

I hypothesised that the use of appropriate methods (defined broadly as a way of recognition, a systematic procedure to obtain or give reason for knowledge) would enable patients and professionals to accomplish a systematic way of thinking, which would empower both parties in problem solving.

Though the methods that nurses and doctors are introduced to during their basic training are slightly different and adjusted to medicine and nursing respectively, what these methods have in common is that they are almost all based on the logic of thought, not empirical data. Although the poor applicability of methods is discussed in nursing, the logic behind such methods can still be recognised in clinical practice, in administrative tools and in procedures and habits more or less taken for granted by health care providers.

In literature studies, one method appeared to fit both the grounded theories and life skills theory. A combination of interests in both the humanities and organisations was the background against which Bos developed a model called dynamic judgment building (in German
“Urteilsbildungsmodell”) between 1968 and 1974 (Figure 1.2). Bos emphasises that the model reflects assessment in groups and was developed in an ideal-typical way on the basis of extensive empirical data, in contrast to most decision-making and problem solving models, which are built on the logic of thought.

Figure 1.2. The model of dynamic judgment building.

Based on a socio-ecological thought, Bos’s view is that participants in a working group must be active. They must create an environment in which questions can grow and mature until fruitful answers appear. This requires the availability of hard facts, which are to be connected through clear thinking, as well as goals that motivate the group and means and routes that help to fulfil these goals. These ecological conditions can be neglected in daily problem solving and decision-making.

The model is characterised by polarity and rhythm. One major polarity is between cognition, dealing with insight, and choice, dealing with decisions. Cognition begins with a feeling of amazement - a person who wants to understand the world clarifies facts through thinking about them and as a result gains insight. A polar relation also seems to exist between facts and thoughts. Choice begins with a feeling of oppression - a person who wants to change the world wants goals to be reached by certain routes. A polar relation seems to exist between goals and routes. Assessment is described as a process of rhythm enacted between the three sets of poles mentioned above: between the two major poles, cognition and choice, and the two sets of poles included within these, the facts and thoughts included in cognition and the goals and routes included in choice.

In communication Bos emphasizes the importance of clarifying who owns a problem. He emphasizes the continued relevance of Socrates’ way of questioning a person by
demanding that they find their own answers to a question – and ensure that the question is relevant to them \(^{59}\) p. 91.

In the middle of Bos’s model is the feeling person \(^{59}\) p. 39. It is important to discover whether any given question belongs to this person and what feelings the person connects with the question. Bos emphasizes the importance of this for a learning process. When the owner has answered the question, feelings are invited through three further questions: How would you express what the person said in your own words? What did the answer do to you? (Recognition? Surprise? Enthusiasm?). With which questions can we continue?

The model offers the possibility for extensive conversation and problem typology. In Bos’s thesis it was adapted to and tested in the practical context of adult education and was proven to increase critical powers of observation of what takes place during decision-making and problem solving. As an employee at the NPI-Zeist Institute for Organisational Development, Bos has used the model in Europe and Brazil in developmental work for group dynamics in organisations \(^{60}\).

Bos has shown that the model could be passed on to and learned by groups. He found that nearly everyone sensed and recognized a “life-process” quality in the model. It also seemed to be possible to find some feeling of balance and rhythm between the poles during a conversation. He stresses that although the abilities needed to deal practically with the model might be developed during a one-week course, they must be developed further by one’s own activity.

In Denmark the model of dynamic judgment building has been used in organisational development \(^{61}\). As far as I am aware, it has not yet been applied in health care work.

1.3.3. The trans-theoretical stages of change theory

As the ability to live with and produce change was considered to be a central part of developing life skills with diabetes, it was considered necessary to include change theory. The stages of change theory developed by Prochaska appeared to be an obvious choice \(^{39}\). This theory was a synthesis of a trans-theoretical study of hundreds of theories combined with empirical studies of people who had succeeded in stopping smoking. The trans-theoretical study was summarised by Prochaska in few essential principles called “processes of change”, providing a definition of change as simple as this:

\begin{quote}
Any activity that you initiate to help modify your thinking, feeling, or behaviour is a change process \(^{39}\), p. 25.
\end{quote}
This definition of change would in diabetes care be consistent with the idea that patients are in charge of deciding the issues of change, which might consist of an alteration of mood or ways of thinking and not just the diabetes specific behaviour suggested by professionals.

A clear distinction between change processes and change strategies was of fundamental importance. While change processes were the same for all people, change strategies were person specific. In itself this point was an argument for conducting the current study. If professionals were to be able to support patients in becoming aware of the strategies available in their situation, proper methods were needed for relational problem solving. Prochaskas’ point of stressing that change is a process and not an event was important and useful for patients as well as for professionals.

Almost all of the change processes identified by Prochaska could be activated and thus covered by GSD: consciousness-raising, social liberation, emotional arousal, self re-evaluation, commitment, and the establishment of helping relationships. The instruments used in GSD were able to specify the stages of change according to 15 different diabetes related issues (WS 3b-c, Appendix D). This instrument was, however, only used as a quick screening instrument to help patients consider their own need and readiness to change and providing an outline of this for further exploration in patient-provider communication. Teaching nurses how to choose the right and most effective process in accordance with the identified stages of change was not included in the study, as GSD covered most of these processes and it was considered that further specification would result in more stress rather than improved effects.
Summary

The theoretical framework was a combination of formal theory and Guided Self-Determination (GSD), which was a synthesis of grounded theories.

The study regarded GSD as being a necessary link between the philosophy of empowerment and the goal of life skills in individual patient care:

- Empowerment (Philosophy)
- Guided Self-Determination based on a synthesis of grounded theories
  - Including trans-theoretical stages of change theory and dynamic judgment-building (Method)
- Life skills with diabetes, which includes balanced self-determinism (Goal)

Using Guided Self-Determination in relational problem solving had two purposes:

1. By having methods, assumed to be counterproductive to empowerment, replaced by GSD, it was expected that an important barrier to empowerment in relational problem solving was removed.

2. As GSD was developed to overcome barriers identified in relational problem solving, it was considered to have the needed apparatus to yield autonomy supportive and effective problem solving.
Reference list


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Chapter 2

Overview of design
2.1. Introduction
This chapter provides a short overview of the research design in the thesis. Further details are given in Chapters 3-7.

2.2. Programmatic qualitative research
The research was designed as qualitative programmatic research\(^1\), a design in which a programme is developed on the basis of qualitative findings and afterwards evaluated qualitatively or quantitatively. This design was recommended by Sandelowski as a way of ensuring that a programme will be perceived as being meaningful for those invited to participate. I had confidence in the ability of qualitative research to reveal processes and barriers which were normally concealed by some of my own profession’s blind spots. Programmatic qualitative research was in addition expected to provide a theory-driven intervention and thus enhance our ability to interpret the result of the intervention as pointed out by Sidani and Braden\(^2\). The programme comprised four phases (Figure 2.1.)

2.2.1. Research setting
As the limited time and other difficult conditions in clinical practice constituted a necessary context for the interpretation of relational problem solving and innovation of methods, busy clinical practice was selected as the setting for the research. This meant that the study was ‘real world research’\(^3\) and this necessitated close co-operation with practitioners to consider both the interests of research and clinical practice.

2.2.2. Developing GSD on the basis of grounded theories
A grounded theory study was conducted in order to interpret processes of importance to the effectiveness of current relational problem solving. Glaser’s advice on grounded theory was followed\(^4\)\(^-\)\(^6\). As mentioned in Chapters 3-5, I acknowledged Glaser’s contention that a researcher’s assumptions can on the one hand be helpful in developing alertness or sensitivity to what is going on but on the other can inhibit the researcher from discovering a new theoretical formulation through emergence\(^7\).
Figure 2.1. Illustration of the study design

Phase 1. Interpretive explanation
(1996-1997)
A Grounded theory study of 11 nurse-patient dyads in traditional care of type 1 and 2 diabetes in poor glycaemic control
- Grounded theories are induced
- A provisional version of Guided Self-Determination is outlined

Phase 2. Participatory research
(1998-2000)
Guided Self-Determination (GSD) is gradually developed and implemented in clinical practice being applied by 25 diabetes patients and 12 nurses supervised by the researcher. Finally, GSD is adjusted to Type 1 diabetes patients with poor glycaemic control and difficulties in living with diabetes.

Phase 3. Qualitative intervention study
(2000-2002)
Clinical significance of GSD is determined when used in one-to-one settings by 11 nurse-patient dyads in order to improve glycaemic control and life skills with Type 1 diabetes. Deductive and inductive analyses validate and further the grounded theories.

Phase 4. Randomised controlled trial
Guided Self-Determination is refined and adjusted to group training and applied in an 8x2-hour session group training program (GSD-GT) for improving life skills with diabetes.

Randomisation of Type 1 diabetes patients with persistent poor glycaemic control

(2001-2002)
Intervention group
Three groups are coached by 6 nurses and researcher in GSD-GT

Control group receive traditional out-patient care

Statement of results after one-year follow-up
GSD-GT 2002-2003
To increase critical awareness of my assumptions and benefit from them in sharpening the focus of the study, I expressed the following ideas on vital issues in mutual decision-making prior to the study: **Patient and nurse:** 1) *Identify, concretise and explicate what the patient finds difficult in daily life with the disease*, 2) *Agree on specific problems to be assessed in order to enable the patient to manage in daily life*, 3) *Achieve mutual recognition of the patient’s current problem solving and exchange knowledge and experience about ideas for improvement*, 4) *Exchange thoughts and feelings as part of overcoming barriers in the recognition process*.  
**Patients:** 5) *Select goals which are consistent with their own developing interests and core values at the end of relational problem solving* and 6) *Perceive fewer problems and conflicts in daily life with the disease after relational problem solving*.  
These assumptions were made concrete operational for observation purposes and the development of interview-guides (Appendix B). A pilot study conducted before phase 1 confirmed that independent interviews with patients and nurses were not sufficient and reliability demanded multiple data including conversations between nurses and patients and between nurses and team members, as is detailed in Chapters 3-5.

### 2.2.3. Participatory research in implementation of GSD in clinical practice

Prior to the study it was decided to use the grounded theories as a basis for developing GSD and subsequently to benefit from the judgments of nurses in refining and implementing the method. This decision was based on the experience that questions exchanged between the health care provider and the researcher would start a fruitful interaction and it was considered that this would enhance the applicability of GSD. The reason for cooperating with patients and nurses in the refinement and implementation of Guided Self-Determination was primarily that it was a way of securing the acceptance and applicability of GSD in busy clinical practice (Chapter 6). In phase 2, nurses and people with Type 1 and Type 2 diabetes participated in the development and implementation of GSD over a 2-year period.

### 2.2.4. Developing the capacity to use GSD

Nurses with more than 1-year’s experience in specialised diabetes care participated in phase 3. In order to develop the capacity to use GSD they all participated in a three-step training programme:
• Theoretical and attitudinal idea of GSD, grounded theory findings and formal theory (lectures)
• Ability to use the worksheets (supervision)
• Advanced communication skills (supervision of application of selected communication skills)

2.2.5. GSD tested in qualitative intervention study
The clinical significance of GSD in one-to-one settings was tested in a qualitative intervention study, phase 3. As the intention was to compare nursing with and without GSD, the research setting in phase 3 was arranged to be similar to that in the grounded theory study. The same series of data were thus collected in the two phases. GSD was used in about 10 conversations, which were scheduled with rather short intervals in between and followed by a period of half a year with longer intervals in between. The qualitative intervention study confirmed the clinical significance of GSD and showed that it produced a substantial change in relational problem solving and in patients’ life skills with diabetes. The qualitative intervention study had a key role in validating and furthering the grounded theories upon which GSD was developed and in addition provided an opportunity to evaluate whether the intervention was effective. The qualitative intervention study thus functioned as a pilot study for the randomised controlled trial.

2.2.6. Adjusting GSD to group settings and preparing a quantitative test in RCT
It was expected that some patients would benefit from GSD in a group setting, which it was also expected would reach more people and cost less (Table 2.1). GSD was therefore adjusted to group-settings and the effects of this were tested in a randomised controlled trial (Chapter 7) as appropriate conditions for using this strong design appeared to be present (Chapter 6). Participation in the RCT followed defined criteria for inclusion and exclusion (Chapter 7, p. 150; Appendix A Figure A2). Participation in the implementation of GSD or the qualitative evaluation of GSD was, for instance, a reason for exclusion. The flow of participants throughout the study is illustrated in Appendix A, Figure A1. The reasons for not inviting 155 patients to participate in the RCT are presented in Appendix A (Table A1).
2.2.7. Recruitment procedure

The group programme comprised eight 2-hour sessions (between 4-6 p.m.) over nine weeks (about the same as the lowest number of hours used in the individual courses). One-week intervals were also the shortest interval seen in the individual courses. The risk of participants dropping out of longer courses was the reason for these choices. To secure an appropriate number of participants in the RCT, patients were invited to participate in two stages: The first invitation was sent to patients with average HbA1 ≥ 8.5, and the second was sent to patients with average HbA1 < 8.5 and ≥ 8.0%. 63% of the first group returned completed questionnaires (32% accepting to participate in group training). 52% of the latter group returned filled in questionnaires (29% accepting to participate in group training). Reasons for refusing to participate were known from the 68 patients who returned the completed questionnaires but refused to participate (Appendix A, Table A2).

Table 2.1. Use of human resources in individual and group based GSD-training

<table>
<thead>
<tr>
<th></th>
<th>Number of hours used by each patient excluding transport and preparation</th>
<th>Number of patients present during the course</th>
<th>Number of professionals present during the course</th>
<th>Number of professional hours used per patient excluding preparation</th>
<th>Number of professional hours used per course excluding preparation</th>
</tr>
</thead>
<tbody>
<tr>
<td>One-to-one setting</td>
<td>8-12</td>
<td>1</td>
<td>1</td>
<td>8-12</td>
<td>8-12</td>
</tr>
<tr>
<td>Group training</td>
<td>16</td>
<td>10</td>
<td>3</td>
<td>4.8</td>
<td>48</td>
</tr>
</tbody>
</table>

The process of converting categories into variables for statistical analysis was facilitated both by knowing the changes caused by GSD and verifying the choice by letting some of the patients test the measurements chosen. On this basis, Health Care Climate Questionnaire (HCCQ)\(^8\), Treatment Self Regulation Questionnaire (TSRQ)\(^8\), Perceived Competence with Diabetes (PCD)\(^9\) and Problem Areas In Diabetes (PAID)\(^9\) were selected (Appendix E, Table E1 and Chapter 7). The translations followed a standardised procedure\(^{10}\) (Chapter 8).
Summary

Facts about the development, implementation and evaluation of GSD.

- Draws on worksheets and advanced professional communication, Appendix D.
- Has been developed on the basis of a grounded theory study and implemented in clinical practice through participatory research 1996-2000 (Chapters 3-5).
- Is adjusted to people with Type 1 diabetes in poor glycaemic control.
- Has been tested in one-to-one settings by diabetes nurses and people with Type 1 diabetes and poor glycaemic control 2000-2002 (Chapter 6).
- Was tested in a 16-hour group course in 2001-2003. 50 people with Type 1 diabetes and persistent poor glycaemic control completed a RCT study testing the effect of GSD one year after the course (Chapter 7).
- Personal patient outcome stated by people one year after attending GSD group courses are sorted in accordance with Brook’s life skills taxonomy before questionnaires (Appendix E).
- It is concluded that GSD has clinical significance in one-to-one settings (Chapter 6).
- It is concluded that GSD has clinical and statistical significance in group settings (Chapter 7).
Reference list


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   Ref Type: Electronic Citation


Chapter 3

Life versus disease in difficult diabetes care

Conflicting perspectives disempower patients and professionals in problem solving

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Abstract

Conflicts in problem solving are known from diabetes research on patients with good glycaemic control, who resent health care providers undervaluing their experiential knowledge. Conflicts in difficult problem solving have rarely been studied from the perspectives of both patients and professionals. The interaction between health care providers and eleven diabetes patients with poor glycaemic control was studied in a grounded theory study at a Danish university hospital. Keeping life and disease apart was identified as a core category involving a pattern of conflict lines between and within patients and health professionals, and disempowering them in problem solving. Three approaches were identified: a compliance expecting approach kept the pattern unchanged, a failure expecting approach deadlocked the pattern and a mutuality expecting approach neutralized the conflict lines through situational reflection and revealed a positive potential in different points of view, which would be easy to exploit in problem solving.

Keywords: Diabetes, chronic care, conflict, grounded theory, problem solving, knowledge.
Introduction

Integrating diabetes into life, or balancing life and disease, have been described as developmental processes requiring that patients assume responsibility for diabetes in their own unique context and in accordance with their values and responses 1-3. According to several studies, a large number of people with diabetes experience difficulties in learning to live with the illness 3-8.

For a considerable group of diabetes patients one major difficulty is achieving improved glycaemic control. Research indicates that up to 50% of diabetes patients have not yet achieved the degree of glycaemic control known to be ideal for preventing disabling complications 9-11. Even under optimised insulin treatment, a residual group of patients do not improve their glucose control 12. The effectiveness of traditional interventions has been questioned. A meta-analysis of 73 published studies showed that glycaemic control only improved temporarily between 1 and 6 months after patient education 13. An intervention study including re-education, dietary advice and insulin dose adjustment for people with Type 1 diabetes, showed that glycaemic control 6 months later improved for about 60% of the patients, while almost 40% showed a deterioration in glycosylated hemoglobin (HbA1c) 14.

Appropriate ways of helping patients to improve glycaemic control in diabetes care have been considered in several studies. These studies conclude unambiguously that paternalistic approaches expecting compliance and adherence should be avoided because they tend to deprive patients of initiative 15. Instead, autonomy supportive approaches such as empowerment and self-determination have proved more reliable, improving patients’ self-efficacy and glycaemic control, and believing in and respecting their ability to take responsibility for their own lives 16;17.

Empirical studies, however, reveal difficulties in realizing autonomy support in clinical practice. In one study, interviews with health care providers revealed that they expected their own role in chronic care to be paternalistic 18. Other studies have found that patients (even those with good glycaemic control), report that health professionals tend to undervalue their experiential knowledge in problem solving 1;19, even when initially inviting them to participate in problem solving 19.

In this article we report on a grounded theory study of difficult problem solving in diabetes care, providing a theoretical account of how patients and professionals approach problem solving. Specifically, we describe a) a central tendency among both patients and health care professionals to keep life and disease apart as distinct entities, b) a tendency among patients and health care professionals to give conflicting prioritisations to life and disease when approaching
problems involved in control of the disease, and c) three different approaches to problem solving which determine whether the conflict remained unchanged, deteriorated or was resolved and replaced by situational reflection which in turn revealed a positive potential in different points of view which was easy to exploit in problem solving. Data are from the initial phase of a 4-phase research program into innovation of methods in relational problem solving conducted at a Danish university hospital between 1996 and 2004.

**Methods**

The study used grounded theory methodology comprising a symbolic interactionist perspective and a constant comparative method.

**Participants**

Eleven patients and eight nurses from an in-patient unit or day clinic at a Danish university hospital were asked and agreed to participate. Inclusion criteria for patients were: a) age ≥ 18 years, b) having been diagnosed with diabetes ≥ 1 year and c) being admitted because of poor glycaemic control (HbA1c ≥8.0%). Nurses were included if they were familiar with traditional diabetes care and had more than 1 year of experience from a specialised diabetes unit. Eight of the patients were aged 18-42 years and had been suffering from Type 1 diabetes for 2 – 25 years (median 9), and three were aged 49-63 years and had been suffering from Type 2 diabetes for 1-4 years. All patients (seven female and four male) with HbA1c 8.4 – 18.0 as an expression for the mean glucose over the last 6 weeks had earlier attended individual or group based diabetes education as conventionally offered by the hospital. Eight nurses with 1-17 years of experience in diabetes care (median 4) participated as “contact nurses”, responsible for the care of the patients.

**Sampling procedure**

Despite poor metabolic control, the first patient included had a high level of resources for managing his diabetes. This patient was highly critical of the approach to care adopted by health care professionals. Following the principles of theoretical sampling, this case generated a hypothesis that interactions between professionals and patients with an imbalance between poorly regulated diabetes on the one hand and high levels of self-management resources on the other would reveal how the power of patients and health care professionals might be used inappropriately. In order to investigate and contrast processes related to the imbalance, subsequent patients were theoretically
sampled to ensure a variation in levels of resources for self-management of diabetes. Seven patients were judged to have high levels of self-management resources, while four patients provided a contrast to this by generally appearing to have low levels of self-management resources. Judgments regarding levels of resources were based on information provided in the patients’ medical records. Further investigation during data collection verified or modified this first impression, leading to the sample included in this study.

**Data sources**

Two conversations between the patient and the nurse were taped from each nurse-patient dyad, one at the beginning and one at the end of the hospital stay, documenting what was discussed, planned, accomplished and evaluated by them (Table 3.1). In addition, each nurse was asked to tape a discussion with a doctor, dietician or another nurse from the team, which she considered to be important in appraising the patient’s situation. These conversations revealed observations, feelings, concerns and ideas exchanged internally among the diabetes team when patients were not present. In each case, all three conversations were listened to before semi-structured interviews were conducted, first with the patients after discharge and then with the nurse, revealing the experiences, considerations and feelings of both parties with regard to the hospital stay. Finally an interview with the patient half a year later revealed how they assessed the outcome of the admission, taking into consideration the change accomplished or not accomplished in daily life with the illness.

Table 3.1. Data collected and taped during and after admission

<table>
<thead>
<tr>
<th>Time</th>
<th>1 At admission</th>
<th>2 During hospital stay</th>
<th>3 Shortly before discharge</th>
<th>4 Shortly after discharge</th>
<th>5 Shortly after patient interview</th>
<th>6 ½ year later</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data type</td>
<td>Conversation between patient and nurse *</td>
<td>Conversation between nurse and colleague about the patient’s situation*</td>
<td>Conversation between patient and nurse*</td>
<td>Semi-structured interview with patient conducted by the researcher</td>
<td>Semi-structured interview with nurse conducted by the researcher</td>
<td>Semi-structured interview with patient conducted by the researcher</td>
</tr>
</tbody>
</table>

* Researcher not present

**Analysis**

The taped interviews and conversations were saved and processed as sound files supported by the Qualitative Media Analyser, a computer program providing simultaneous access to the original
auditory details of the data and connected transcriptions and notes during coding. The inductive process of applying constant comparative analysis, as recommended by grounded theory, was performed in four steps. Firstly, initial open coding was performed on each conversation or interview soon after it had taken place. Through a combination of listening and writing notes, in vivo codes were discovered, providing ideas for the tentative advancement of more abstract codes. Secondly, a critical comparison focused on the most solid and insisting categories, which were now supported by transcriptions of the coded data. This was used to specify the content and further the advancement of lasting categories and sub-categories. Step two ended when saturation was achieved and ideas for tentative links between categories appeared to emerge. During the third step comparison across data sources was performed to explore and confirm links between concepts and thus pattern out theoretical ideas and connections. These initial, theoretical constituents were compared in the fourth step, which continued throughout the process of writing, in order to connect them into larger constituents for further theory building. At each step, returns were made to former steps in order to test ‘fit’, ‘work’, ‘relevance’ and ‘modifiability’.

When, for instance, the surprisingly hostile attitude to professionals shown by the first patient was compared to seemingly different attitudes shown by other patients such as resisting mutely and doing as they were told, resemblances appeared suggesting that they were all properties of the category resisting professionals. Links were identified between this concept and professional pressure, as both were connected with the core category Keeping life and disease apart. Continuous comparison revealed three approaches to problem solving which influenced this pattern.

Validity

Validity was considered at several levels. We acknowledged Glaser’s contention that a researcher’s assumptions can on the one hand be helpful in developing alertness or sensitivity to what is going on but on the other can inhibit the researcher from discovering a new theoretical formulation through emergence. To increase critical awareness of our assumptions and benefit from them to sharpen the focus of the study, we expressed our ideas on vital issues in mutual decision-making prior to the study. Multiple data sources were included in order to increase the reliability of the study. A pilot study convinced us that interviews with patients and nurses individually were not enough. In order to know what was going on in problem solving we had to know what actually happened during patient-provider conversations. In order to provide a reliable impression of the care delivered, conversations were recorded at strategic times at the start and end of the hospital
stay. Barriers to taking action were revealed by asking nurses to tape the reflections they shared with each other while planning the care. It was also considered that a better understanding of how patients valued the care would be achieved by interviewing them twice at different intervals after discharge. Being aware that the character of a conversation might change because patients and professionals might be distracted by a researcher being present, we chose to ask permission for the interaction between patient and nurse to be tape recorded without the researcher’s presence. The aim was to capture a reliable image of the usual care in daily practice by asking nurses to ‘do as usual’. If they wanted to be especially competent, it was suggested that they be ‘especially competent in doing as usual’.

**Ethics**

Informed consent was obtained from all participants, who were assured that their statements would be handled anonymously and confidentially. The protocol was prepared in accordance with the Helsinki declaration and approved by the ethics committee of Aarhus County.

**Findings**

A pattern emerged around the core category of *keeping life and disease apart*, involving conflict lines within and between patients and professionals. Though sharing the goal of improving glycaemic control, patients and professionals gave opposing prioritisations to life and disease in problem solving. Three approaches to problem solving decided the fate of the conflicts. They remained unchanged in a *compliance-expecting* approach, deteriorated in a *failure-expecting* approach and were diminished or resolved in a *mutuality-expecting* approach. In the following we will detail *keeping life and disease apart*, the conflicts within and between patients and professionals and the three approaches to problem solving.

**Keeping life and disease apart**

Disconnected and conflicting tendencies in keeping life and disease apart, formed lines of conflict within and between patients and professionals. Those involved were apparently unable to find a way through these conflicts (Figure 3.1).
Conflicts within patients and professionals

The conflict within patients consisted of living as well and as normally as possible yet keeping disease at a distance by refusing to allow it to be an integrated part of their lives. The judgments and choices made by the patients thus seemed inconsistent with the answers they provided about what was valuable, necessary, true or possible for them in living with diabetes. Missing or dubious connections between life and disease thus appeared to be a general component of the problems patients perceived in living with diabetes. Different kinds and degrees of resistance to connecting life and disease appeared. Although in principle knowing how to manage diabetes, living in a way that was inconsistent with this knowledge was a typical kind of resistance, which most patients were
aware of and remarked on themselves. Consequently necessary changes in daily life with the illness were not carried out or were carried out reluctantly. Without justification some patients blamed the disease for unrelated problems they experienced. A failure to assume responsibility for diabetes also appeared to varying extents.

Sometimes resistance to the disease was revealed through the metaphors patients used about living with diabetes, such as: “I couldn’t stand living on a leash”, which was used by a patient who described her attitude to diabetes as follows: “I am not adjusted to it”, “I can’t be bothered to live in this regulated way”. “It may well be that I have not accepted it”. Another metaphor, “diabetes is a vermin that you carry around with you”, was used by a young woman. This statement stood in sharp contrast to her behaviour, which indicated that she apparently prioritised the disease over life. On admittance she described her history by using pages full of disease-specific notes about physical symptoms, examinations and treatment. She also negotiated with doctors for more examinations. Interviews, however, supported the metaphor and showed that living with diabetes was extremely difficult for her. She regretted that the team solely concentrated on the “purely physical...You know, I think that it is a deficiency in the system that you don’t talk about psychological things”. Her behaviour was thus explained by a comprehensive, complicated and probably painful disconnection of life and disease, from which she tried to escape by forcing herself to match professionals’ disease-over-life priority. All the other patients more obviously prioritised life over disease.

Professionals limited their role to that of being experts on disease, investigating physical symptoms or typical disease-related problems. This disease-over-life approach to problem solving was apparent right from the time of admission, as shown in the initial conversation between patient number one, a 29 year-old man, and the nurse in a day unit:

**Patient:** But what is your programme? I mean, what is your routine like here?

**Nurse:** Our routines are, well, we take a lot of routine tests umm... kidney test, blood sedimentation, haemoglobin, and all those routine tests umm... and then you hand in a specimen of urine so we can check your kidney function and umm... you follow this (teaching programme) as much as you can, feel like and are interested in, and then along the way we talk, of course, about if you have any problems to try and solve them...

Professionals relied on laboratory values and disease-specific or rule-based knowledge of treatment and care in their deliberations with the patients. As a consequence they had limited knowledge of
each particular patient’s life and possible difficulties in connecting life and the disease. Paradoxically professionals exchanged assumptions about such difficulties in conversations with each other and thus revealed a covert interest in these aspects without letting the patients know.

**Conflict between patients and professionals**

Patients and professionals were generally not conscious of the conflict between them, which consisted of opposing and conflicting priorities of life and disease as discussed above. The relationship between them was dominated by the professionals’ disease-over-life priority (Figure 1). A lack of mutual and effective problem solving was indicated by pressure or reluctance shown by professionals and resistance or despondency shown by patients.

Patients on their part appeared to accept the disease-over-life approach and to put on a brave face. Covertly, however, they resisted the perspective of the providers and approached the situation from a life-over-disease priority in which their own experiences and difficulties in living with the illness were seen as most important. The patient above even felt de-personalized by the health care providers’ disease-oriented view, perceiving it as undervaluing the rather painful difficulties he experienced in living with the illness:

> When I am sitting here as a patient I have a malfunctioning pancreas. That is what they study and consider and look at. And then they measure some values, and then they adjust the medication....so that the results look better. If I was sitting here as a person, then we would not have to go through all this talk about results. Then we would also talk about how the person was doing: “How is your family coping with your diabetes? What are your thoughts about the late complications?” Now I have had laser treatment on my eyes. “What thoughts have you had about that?”

This patient had no sense that professionals were aware of his concerns about his eyes. Although they were, they did not use it explicitly in their interaction with the patient – as is clear from the following discussion between the contact nurse and a doctor one day during rounds:

Nurse: *Isn’t it also your experience in the out patients’ clinic that he has been difficult to motivate and....*

Doctor: *Yes, you become involved in such theoretical discussions, which means that you lose sight of the real point. It is very interesting because he knows a lot about the hospital world and so on. Then you end up discussing some detail, which makes it difficult - it might be that he is more frightened than you think. I do believe that he is worried about the problems with his eyes.*
As both parties were generally not conscious of the origins of such conflicts of priority, the conflicts were usually unresolved and tended to become personal as a result of failed problem solving, starting a vicious circle of intensified pressure from professionals opposed by intensified resistance from patients.

Patient resistance to the disease-oriented view of professionals apparently tended to accumulate over years becoming more or less a constant part of their attitude, as illustrated at admission by the patient above, who had been living with diabetes since the age of four: “I’m telling you, it is with a gun to my head that I have come!”.

Resistance to professionals was stated clearly by this patient in the form of anger and sarcasm. For instance, in the interviews he referred to conversations with physicians as “being granted an audience with the high consultants” and laughingly described their conferences “when they are holding their little meetings in the morning, conferences they call it”. Other patients, however, showed resistance in a more subtle form by, for instance, remaining silent or ignoring the suggestions of professionals.

Five patients connected professional undervaluing of their experience to the fact that they had poor glycaemic control. One patient described professionals as “putting themselves on a pedestal”. Patients perceived that they were assigned the role of recipients of professional knowledge and not valued as sources of knowledge about their own life with the disease. A 32 year-old woman expressed it this way:

My knowledge?? Well they don’t want to know……. It is like being put in a box that says: This is a diabetic who can’t manage (laughs), and then they don’t want to know about your experience because you can’t do it right anyway – so it is the wrong experience.

Although perceived undervaluing caused resistance to professionals in the form of anger and distress, these reactions seemed to be more or less concealed from professionals. Patients seldom allowed those who had caused their resistance to become aware of it. Usually they would behave as if nothing was wrong when they met with these professionals and only discuss their dissatisfaction with other patients or perhaps with other professionals.

Professionals in general were very sensitive to patient resistance and perceived it at least indirectly. On the one hand they felt obliged to take care of such patients. On the other, they felt uncomfortable doing so and tended to avoid them. Two of the patients, who obviously resisted the advice of health care professionals were described as being “difficult” or “lacking motivation”.

Often resistance emerged in situations where the patient’s point of view or ability to choose freely were threatened. Resistance seemed thus to develop if patients perceived increased pressure from professionals to obtain specific changes or when the suggested changes conflicted with valued and prioritised activities and goals in the patient’s life. Even if the power appeared to lie with the professionals, they seemed to be powerless in the face of patient resistance such as, for example, when a patient refused or postponed taking prescribed medicine or when patients stayed away from the out-patient clinic or from diabetes education.

**Approaches to problem solving**

The conflict between patients and professionals tended to divert attention away from difficulties perceived by the particular patient in connecting life and disease. The providers’ limited knowledge of these difficulties seemed to be connected with the fact that their impressions of these difficulties were seldom revealed to patients. They thereby missed the chance of having their assumptions confirmed, rejected or supplemented by the patients and their impressions remained unverified hypotheses with no impact or only a dubious impact on problem solving. Three different approaches taken to problem solving appeared to influence the conflict pattern differently (Table 3.2).

**Compliance expecting approach**

In seven dyads a compliance expecting approach to problem solving was seen, in which the overall conflict remained unchanged as the different points of view remained concealed. In this approach professionals appeared to perceive patients as having a problem, which they as professionals were responsible for solving. They used their power in the form of general and mostly disease-specific knowledge to address the perceived problem. However, this knowledge seemed to be of limited value when not connected with specific knowledge of the difficulties experienced by the patients in living with the illness. Being expected to comply, patients hardly used their own power in problem solving interactions, or used it counter PRODUCTively in the form of resistance to professionals.

Perceiving health care professionals’ narrow perspective of their situation tended to reduce patients’ expectations of professional help. A 43-year old woman with Type1 diabetes expressed it in this way:

*They can come up with some good ideas. Suggest that I might take that much insulin, but I can’t use them for much else.*
Table 3.2. How approaches to problem solving influence the conflict.

<table>
<thead>
<tr>
<th>Problem solving approach</th>
<th>Professionals’ view of patient</th>
<th>Patient’s view of professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Failure expecting approach:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conflict deadlocked</td>
<td>Patient is a problem</td>
<td>Professionals have had their chance</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(2 dyads)</td>
<td></td>
</tr>
<tr>
<td><strong>Compliance expecting approach:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conflict unchanged</td>
<td>Patient has a problem which we can solve</td>
<td>Professionals decide without knowing my difficulties in living with the illness</td>
</tr>
<tr>
<td></td>
<td>(7 dyads)</td>
<td></td>
</tr>
<tr>
<td><strong>Mutuality expecting approach:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conflict resolved. Situational reflection takes advantage of a potential for change in different points of view</td>
<td>Patient is a problem solver</td>
<td>Professionals know my difficulties in living with the illness and support me in solving them</td>
</tr>
<tr>
<td></td>
<td>(2 dyads)</td>
<td></td>
</tr>
</tbody>
</table>

Meeting professionals with *reduced expectations* seemed to increase the tendency to underplay the conflict. Letting professionals keep responsibility for problem solving appeared to be the patients’ mute way of resisting or resigning themselves to professionals’ disease-over-life priority. An example of mute resistance was *doing as they were told*, which was seen when professionals took a simplistic view of problems and rebuked patients for not following the rules, without understanding what was really difficult for them. When doing as they were told, patients did precisely what a professional told them to despite the fact that they were convinced that in their case this was the wrong decision and would turn out badly. A 54 year-old woman with Type 1 diabetes, for instance, reacted in this way because she was rebuked at the diabetes clinic for not taking the insulin properly and told by a doctor to take it without any adjustments. Though she knew it would turn out badly, she did as she had been told, as her way of resisting the doctor:
Last time I was told to tighten up and keep control and take my insulin myself. This meant that I felt rather awful for three months. – It fluctuated between too high and too low. I suffered a lot then. Yes, I had much too much (insulin).

When patients experienced professionals making decisions without asking for their opinion, they could also resist by refusing to comply. This occurred when the patient in dyad 1 was being put on new medication. During interviews the patient said that at the moment he was nervous because he was about to have his eyes laser treated. The nurse was present at the time and recalled the decision as follows.

I remember ... he wasn’t asked if he was happy with this. I believe the doctor took it for granted... well this was how it should be... and there was something about writing notes. He (the patient) didn’t really have the opportunity to say no... so unfortunately he wasn’t involved in the decision there.

The patient would have preferred to have the new medication postponed for a couple of weeks, expecting that difficulties in distinguishing between the side effects of the new medicine and symptoms resulting from fluctuations in blood sugar would require his full attention. Resenting the way the medication above was prescribed, he did not take it for months.

**Failure-expecting approach**

A pressure-resistance spiral seemed to develop only to a certain point. In cases of persistent failure of problem solving, professionals changed their attitude to one of reluctance, giving up and withdrawing from patients. The patients for their part became despondent.

Professionals showed different degrees of reluctance when caring for patients, from slight irritation expressed as a sigh by a nurse who had to ask a patient the same question three times, to strong aversion expressed when problem solving had failed to the extent that the patient himself had become the problem. A nurse who took care of a young man of eighteen expressed strong aversion in this way:

I think that many colleagues in here have got him stuck in their throats. He has been here so many times. It is the same every time. He is a problem here instead of being a possibility. It has something to do with our point of view and it is that point of view that shines through because we see the problem. It is a huge big problem that walks through the door when he arrives – Well it is!
When regarding patients as being a problem, professionals were no longer able to distinguish patients from their problems. This seemed to be the worst position in terms of recognizing patient potential and being open-minded about noticing new aspects of a patient’s behaviour. In the above case, for example, the nurse displayed a fixed view of the patient, as she mistakenly believed that an event from an earlier admission had actually happened during the current one.

In two dyads the general conflict was deadlocked in this way. Further problem solving seemed to consist of half-hearted attempts, which both health care professionals and patients expected to fail. "They have had their chance", said a patient in an interview 6 months after a hospital stay, commenting on the fact that she had just turned down another admission to have her diabetes regulated. By saying "They" and "their" she implied that she perceived health care providers to be responsible for the disappointing results of her admission six months previously.

The ultimate decision for patients in the failure expecting approach seemed to be to stay away from the clinic, consult another clinic or go to their general practitioner instead. Four of the patients had made such a decision earlier in life.

**Mutuality-expecting approach**

The whole approach to problem solving appeared to change when patients’ difficulties in connecting life and disease were addressed openly by one of the parties. When perceiving that professionals explicitly acknowledged these difficulties, patients changed from being mute to talking about them.

In two dyads, a mutuality-expecting approach characterised problem solving. In this approach professionals appeared to regard patients as problem solvers, exploring and challenging their current problem solving strategies in connecting life and disease. By exchanging different points of view on these strategies, patients and professionals seemed to match each other’s priorities and combine disease-oriented and life-oriented knowledge. A person-specific knowledge of difficulties in connecting life and disease was thus co-created, revealing a difference of opinion between patients and professionals about these difficulties, which appeared to have a positive potential for solving problems effectively.

In a conversation with the patient on admission, the nurse in one dyad spontaneously remarked on a difficulty she hypothesised as being one of “not having accepted the disease”. Another of the patient’s difficulties was hypothesised by the doctor and mentioned as “blaming everything on her diabetes” in a conversation between the patient, nurse and doctor during rounds.
The resistance both internally and between patient and professionals here came into the open. According to the nurse the patient at first rejected the physician’s claim, maintaining that: “He was not the one who has diabetes!”. However, after discussing it openly at great length, all three of them could laugh about it. Nothing much was said about it afterwards. The patient needed time to “digest” it. She came back a few days later and said that she had thought about it and realized that it was true. The patient asked afterwards to see this doctor every time in the out-patient clinic. Upon discharge this conversation was described by the nurse as: "What benefited the patient most during the entire admission". It was also emphasized as something special and important by the patient in interviews:

_I have also experienced something else. That doctor X, I experienced him differently. He saw me more like a whole person, not just the diabetes. It gives you something to think about. Because he said, “Now don’t blame everything on the diabetes. Other things have happened in your life. You have started a new job and such like, right? This gave me something to think about, because I have known deep down that this was part of it. It had something to do with me feeling absolutely awful._

Another patient suffered from forgetfulness because of painter’s syndrome. This impaired memory problem was remarked on several times by the patient himself at admission. As the patient’s treatment was going to be changed from tablets to insulin during this admission, the nurse discussed with a colleague how they should take this forgetfulness into account when providing information to this patient about the necessary precautions related to insulin treatment. They decided as a simple solution to select only the essential information and write it down on a slip of paper. Knowing his own ability to read messages, however, the patient at first refused to accept the slip, asking the nurse to write it in block capitals, which she did. When the patient for the first time experienced symptoms of low blood sugar he was out shopping. He remembered the slip in his pocket and the information on this slip helped him manage the situation.

**Diskussion**

The core category of keeping life and disease apart identified in this study is an important finding, adding knowledge of difficult problem solving to existing research. Patients with good glycaemic control have described how they succeeded in integrating diabetes into their lives after reaching a turning point and changing their emphasis from trying to live a normal life to trying to live a normal life without jeopardizing diabetes management. The fact that all the patients in our study prioritised a normal life and more or less disregarded diabetes, and that all had poor glycaemic
control indicated that they had probably not yet reached such a turning point in their attitude to diabetes as described by Hernandez. According to our study, the interactions with health care professionals did not contribute to helping patients with this process. On the contrary, pressure may increase non-compliance in accordance with reactance theory 27, which argues that threats to freedom will make people feel more attracted to doing what they have been forbidden to do. Even the despondency observed in patients in the failure expecting approach can be seen as a result of prolonged resistance 28. The consequences of a compliance-expecting approach thus seem to be far more serious in the care of patients with poor glycaemic control than in the care of patients with good glycaemic control.

The advantages of mutuality in problem solving suggested in two dyads in our study is supported by other studies, which have found that mutuality increased effectiveness 29-31. Mutuality can be seen as the mid-point of a continuum between paternalism at one extreme and autonomy at the other 32. The existence of a paternalistic starting point in clinical practice was indicated in our study, as nine out of eleven relationships were either failure or compliance expecting. Moving towards autonomy support, which has proved effective in improving glycaemic control 17, would thus mean a movement in the direction of mutuality.

For professionals, life and disease invariably appeared to be separate when they met a ‘new’ patient and remained so until they had co-created a person-specific knowledge together with this particular patient as a way of understanding and solving the problems perceived by him or her. Empathy, proposed as “a way of knowing” the patient, has been contrasted with pseudo-empathy 26. Our study identified the danger of mistaking impressions for verified knowledge and revealed that the decisive failure occurred when professionals did not verify their impressions of person-specific difficulties in connecting life and disease because they neglected to disclose them to patients. Such disclosure was already recommended forty years ago in the tradition of interactive problem solving 33-35.

As professional interest in the person-specific difficulties of living with diabetes was not confided to patients, they might in turn perceive the care offered as pure ‘healthism’ - an idealism 36 defined in health promotion as “the belief or cultural value that health is more important than all other rewards or satisfactions” meaning that the achievement of health would be regarded as “the prime object of living”. Knowing the complex choices they face in daily life with diabetes 37, patients will perceive this simplification as an insult to important life values and an improper encouragement to discount these values.
The extent of the conflicting priorities of life and disease seemed to be connected with a lack of awareness of its existence. Our findings even suggest that demystifying conflicting perspectives among health care professionals and patients is an essential premise for succeeding in mutual problem solving. A tension, which was difficult for both patients and professionals to tolerate, seemed to be present before an exchange of different points of view but then disappeared as such exchanges became overt and situational. When revealed in mutual situational reflection, different points of view seemed to possess a potentiality for change in bridging life and disease, which could be easily exploited in problem solving. This is in line with McNamee and Gergen (1999), who assign a positive potential to conflicts and see them as a natural and inevitable outcome of social existence. Perceiving power as a positive and inevitable aspect in relationships, the philosopher Løgstrup maintained that the relevant ethical question was how to use power appropriately, i.e. how to act to the best of one’s judgment in a given situation, rather than attempting to avoid power all together. Fear of revealing difficult feelings and different points of view seemed to prevent patients and professionals from using their power appropriately in nine out of eleven dyads.

In line with another study, some patients felt depersonalised by professionals who did not ask for their judgements. The developmental distinction between acting as an individual by distinguishing oneself just by being different from others, and acting as a person by following one’s own judgement of what is needed in a situation, has been expressed in life philosophy. This distinction suggests that treating patients as persons will not be achieved through recognition of outer individual differences, but rather by asking for their personal judgements concerning important issues in life with diabetes. This seems to point to the need for life skills training, proposed by Wodarski as the treatment of choice or alternatively for methods such as dynamic judgement building. The value of knowing the judgements that lie behind seemingly failed diabetes behaviour is also supported by Blumer, who states that poor acts, just like all other acts, are constructed out of what people take into account during their construction.

**Conclusion**

We conclude that the tendency of patients and professionals to keep life and disease apart was central in a pattern of conflicting life-versus-disease priorities, which in turn disempowered them in solving problems in difficult diabetes care. As a solution we found a mutuality expecting approach vital to problem solving. It replaced the general conflict with situational reflection, which appeared
to take advantage of the potential for change in different points of view. Person specific knowledge of difficulties in living with the illness seemed to be co-created during this reflection, bridging the gap between life and disease and enhancing problem solving.

A tension related to the fear of revealing difficult feelings and different points of view at a situational level appeared to precede initiatives to address person-specific difficulties in connecting life and disease. Further research is needed to understand how this tension is tolerated in different patient-provider relationships and through different communicative paths in problem solving.

Acknowledgements
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This article adds:

**Keeping life and disease apart**

Life-versus-disease conflict within and between patients and professionals.

Professional pressure - Professional reluctance.
Patient resistance - Patient despondence.

Compliance expecting approach – Patient having a problem.
Failure expecting approach – Patient being a problem.
Mutuality expecting approach – Patient being a problem solver.

Life skills with diabetes a seldom approached dimension in patient care.
It is suggested to approach patients as problem solvers.

Implications for GSD:

Scope of problem solving is suggested to include difficulties in developing life skills with diabetes.
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Chapter 4

Relational potential for change

Types of relationships in difficult diabetes care

Vibeke Zoffmann RN MPH and Marit Kirkevold RN EdD
Abstract

Background. Potential for change in patient-provider relationships may be exploited to different degrees depending on type of relationship. Till now we have limited knowledge about the effectiveness of relationships established between patients and providers in clinical practice.

Aims. The aim of the paper is to detail relational potential for change developed in a grounded theory study of patient-provider interaction in difficult diabetes care.

Methods. The interaction in dyads between eleven people with diabetes in poor glycaemic control and eight nurses was studied during relational problem solving using grounded theory methodology. Conversations between patients and nurses and between nurses and either a doctor, a dietician or another nurse were analyzed along with separate semi-structured interviews with patients and nurses after discharge and with the patient again 6 months later. Data are from the initial phase of a research program into innovation of methods in relational problem solving conducted at a Danish university hospital between 1996 and 2004.

Findings. A core category of relational potential for change was identified. Around this category appeared a pattern of three types of relationships named according to their way of handling I-you boundaries. Professionals mostly shifted between two types of relationship, I-you-distant provider-dominance and I-you-blurred sympathy. A third relationship, I-You-sorted mutuality, was rarely seen and not yet fully evolved. The relationships differed in: a) scope of problem solving, b) roles assigned to the two parties, c) awareness of difficult feelings and different points of view and d) the quality of knowledge they achieved as the basis of problem solving.

Conclusions. I-you-sorted mutuality appeared to be the most effective framework for relational problem solving in difficult diabetes care. Implications for practice and further research are discussed.

Keywords: Relationship, diabetes, mutuality, roles, knowledge, change, grounded theory.
**Introduction**

Patient-provider relationships may play a neglected role in chronic care in terms of the degree to which the potential for change is exploited in problem solving. In difficult diabetes care, failed problem solving over several years provides a reason for studying patient-provider relationships and their influence on the effectiveness of problem solving.

**Background**

Different models of patient-provider relationships have been analysed on the basis of theoretical and philosophical concerns. Roter concluded that neither authoritarian guidance nor independent decision-making should be recommended as the best alternatives for an optimal client-provider relationship, but rather a relationship based on partnership and the active participation of both clients and providers.¹

Research has shown positive health outcomes as a result of autonomy support and empowerment³⁻⁴⁻⁵ and the acknowledgement of empowerment seems to be widespread⁶⁻⁷ in diabetes care. A qualitative study of diabetes patients’ experiences of empowerment in clinical practice concluded, however, that professionals’ proclaimed intention to use empowerment was seldom perceived by patients. Patients rarely experienced that professionals were interested in listening to their opinion concerning their health problems². The intention to use empowerment in clinical practice thus seems to fail frequently.

Ideal relationships may appear to be rather theoretical, undocumented and unverified. Egalitarian relationships between patients and professionals have for instance recently been questioned by Thorne who warns against a tendency to uncritically adopt equality as an incontestable and overarching truth and to overlook its limitations⁸. Our knowledge of relationships thus requires empirical and critical foundations.

**Aim**

The aim of the paper is to present an interpretation of patient-provider relationships, which constitutes one of three interrelated studies on the effectiveness of relational problem solving between patients and professionals in difficult diabetes care.
**Method**

The study used grounded theory methodology comprising a symbolic interactionist perspective \(^9\) and a constant comparative method \(^{10-13}\).

**Participants**

Eleven patients and eight nurses from an in-patient unit or day clinic at a Danish university hospital were invited and agreed to participate (Table 1). Inclusion criteria for patients were: a) age $\geq 18$ years, b) diagnosed with diabetes $\geq 1$ year and c) admitted because of poor glycaemic control (HbA1c $\geq 8.0\%$). Nurses were included if they were familiar with traditional diabetes care and had more than 1 year of experience in a specialised diabetes unit. Eight of the patients were aged 18-42 years and had been suffering from Type 1 diabetes for 2 – 25 years (median 9). Three were aged 49-63 years and had been suffering from Type 2 diabetes for 1-4 years. All patients (seven female and four male) with HbA1c 8.4 – 18.0 had attended individual or group based diabetes education as conventionally offered by the hospital. Eight nurses with 1-17 years of experience in diabetes care (median 4) participated as “contact nurses”, responsible for care of the patient.

**Sampling procedure**

Despite poor metabolic control, the first patient included had a high level of resources for the self-management of diabetes. This patient was highly critical of the approach to care adopted by health care professionals. Following the principles of theoretical sampling, this case generated a hypothesis that interactions between professionals and patients who displayed an imbalance between poorly regulated diabetes on the one hand and high levels of self-management resources on the other would reveal how the power of patients and health care professionals was perhaps being used inappropriately. In order to investigate and compare the processes related to this imbalance, subsequent patients were theoretically sampled to ensure a variation in levels of self-management resources. Seven patients were judged to have high levels of self-management resources. Four patients appeared to have low levels of self-management resources. These assessments were based on information in the patients’ medical records. Further investigation during data collection verified or modified this first impression, leading to the sample included in this study (Table 4.1).
Table 4.1. Characteristics of patient-nurse dyads in grounded theory study.

<table>
<thead>
<tr>
<th>Dyad number</th>
<th>Sex F/M</th>
<th>Age years</th>
<th>Type of diabetes</th>
<th>Illness duration years</th>
<th>Late complications</th>
<th>Day and night (D&amp;N)/day unit (D)</th>
<th>Type of treatment</th>
<th>Nurse experience in diabetes care</th>
<th>Conversation with colleague</th>
<th>Hb A1c at admission</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>M</td>
<td>29</td>
<td>1</td>
<td>25</td>
<td>Yes</td>
<td>D</td>
<td>Insulin</td>
<td>8/7</td>
<td>Physician</td>
<td>9.9</td>
</tr>
<tr>
<td>2</td>
<td>F</td>
<td>54</td>
<td>1</td>
<td>2</td>
<td>No</td>
<td>D</td>
<td>Insulin</td>
<td>36/17</td>
<td>Dietician</td>
<td>8.4</td>
</tr>
<tr>
<td>3</td>
<td>M</td>
<td>18</td>
<td>1</td>
<td>3½</td>
<td>No</td>
<td>D&amp;N</td>
<td>Insulin</td>
<td>4/2</td>
<td>District nurse</td>
<td>18.0</td>
</tr>
<tr>
<td>4</td>
<td>M</td>
<td>63</td>
<td>2</td>
<td>4</td>
<td>Yes</td>
<td>D&amp;N</td>
<td>Insulin replaces tablets</td>
<td>12/1</td>
<td>Nurse</td>
<td>9.0</td>
</tr>
<tr>
<td>5</td>
<td>F</td>
<td>34</td>
<td>1</td>
<td>20</td>
<td>Yes</td>
<td>D&amp;N</td>
<td>Insulin</td>
<td>11/4</td>
<td>Not taped</td>
<td>9.3</td>
</tr>
<tr>
<td>6</td>
<td>F</td>
<td>42</td>
<td>1</td>
<td>14</td>
<td>No</td>
<td>D</td>
<td>Insulin</td>
<td>8/7</td>
<td>Dietician</td>
<td>11.0</td>
</tr>
<tr>
<td>7</td>
<td>F</td>
<td>49</td>
<td>2</td>
<td>2</td>
<td>No</td>
<td>D</td>
<td>Diet</td>
<td>36/17</td>
<td>Dietician</td>
<td>8.5</td>
</tr>
<tr>
<td>8</td>
<td>F</td>
<td>55</td>
<td>2</td>
<td>1</td>
<td>No</td>
<td>D</td>
<td>Tablet</td>
<td>16/15</td>
<td>Dietician</td>
<td>10.7</td>
</tr>
<tr>
<td>9</td>
<td>M</td>
<td>20</td>
<td>1</td>
<td>2½</td>
<td>No</td>
<td>D&amp;N</td>
<td>Insulin</td>
<td>3/3</td>
<td>Team</td>
<td>11.0</td>
</tr>
<tr>
<td>10</td>
<td>F</td>
<td>43</td>
<td>1</td>
<td>3</td>
<td>No</td>
<td>D</td>
<td>Insulin</td>
<td>5/4</td>
<td>Dietician</td>
<td>11.0</td>
</tr>
<tr>
<td>11</td>
<td>F</td>
<td>32</td>
<td>1</td>
<td>23</td>
<td>Yes</td>
<td>D&amp;N</td>
<td>Insulin</td>
<td>3/3</td>
<td>Nurse</td>
<td>12.0</td>
</tr>
</tbody>
</table>

Data sources

As the primary sources, two patient-nurse conversations were taped from each dyad, one at the beginning and one at the end of the hospital stay. They documented what was discussed, planned, accomplished and evaluated. In addition, each nurse was asked to tape a discussion with a doctor, dietician or another nurse from the team, which she considered to be important in assessing the patient's situation. These conversations revealed observations, feelings, concerns and ideas exchanged internally in the diabetes team when patients were not present. In each case, all three conversations were listened to before semi-structured interviews were conducted, first with the patients after discharge and then with the nurse, revealing the experiences, considerations and feelings of both parties with regard to the hospital stay. Finally, an interview with the patient half a year later revealed how they assessed the outcome of the hospital stay, taking into consideration the changes accomplished or still unaccomplished in daily life with the illness.

Analysis

Data were concurrently analysed by the first author supported by the Qualitative Media Analyser (a computer program providing simultaneous access to the original auditory details of the data and connected transcriptions and notes during coding). Constant comparative analysis as recommended by grounded theory was performed through a combination of listening and writing notes, firstly on single data sources and then across data sources.
Sudden shifts in the nurses’ approach to patients, which occurred when patients expressed criticism of the health care system or expressed difficult feelings related to diabetes, put the analysis on the track of the first type of relationship: *I-you blurred sympathy*. Further analysis revealed that sudden shifts to this type of relationship apparently occurred spontaneously on the initiative of nurses when tensions between a patient and nurse became high. *I-you blurred sympathy* thus appeared to function as a spontaneous compensation for the weaknesses of an *I-you distant provider dominance* relationship. Continued comparison revealed an alternative type of relationship: *I-you-sorted mutuality*. Differences between the three relationships were subsequently organized in a matrix pointing at a core category of *relational potential of change*, differently exploited in the three relationships (Table 4.2).

**Validity**

The six data sources available increased concurrent validity in the constant comparison that resulted in this interpretation of patient-provider relationships. Data sources thus allowed us to compare the observed patient-nurse interaction in two situations with the way that both parties independently referred to the interaction: the nurse in a conversation with a colleague and in an interview; the patient in two interviews at different times.

Being aware that the character of a conversation might change because patients and professionals might be distracted by a researcher’s presence, we chose to ask permission for the interaction between patient and nurse to be taped without the researcher being present. The aim was to capture a reliable image of the usual care in daily practice by asking nurses to ‘do as usual’. If they wanted to be especially competent, it was suggested that they be ‘especially competent in doing as usual’.

**Ethics**

Informed consent was obtained from all participants, who were assured that their statements would be handled anonymously and confidentially. The protocol was prepared in accordance with the Helsinki declaration and approved by the ethics committee of Aarhus County.

**Findings**

A core category of *relational potential for change* was identified and comprised of a pattern of three kinds of relationships (Table 4.2) 1) *I-you-distant provider-dominance* 2) *I-you-blurred sympathy*, and
### Table 4.2. Relational potential for change. Grounded theory developed in difficult diabetes care.

<table>
<thead>
<tr>
<th></th>
<th>I-you distant provider-dominance</th>
<th>I-you blurred sympathy</th>
<th>I-you-sorted mutuality</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Scope of problem solving</strong></td>
<td>Implicitly decided by the professionals comprising biomedical problems or problems typical for the patient group.</td>
<td>No specific subject for problem solving is chosen. With a diffuse and non-delimited scope professionals focus on similarities between the patients’ and their own situation as a means of establishing contact.</td>
<td>Explicitly specified, comprising what the two parties assess as being currently important and difficult for the patient.</td>
</tr>
<tr>
<td><strong>Roles assigned the two parties in problem solving</strong></td>
<td>The professionals are in charge, expected to be sole investigators finding solutions to the problems. The patients are expected to follow the professionals’ suggestions. Importance is attached to professionals’ limited time. Patients are bored.</td>
<td>Problem solving recedes into the background. Professionals are emotionally involved, aim at establishing and keeping contact by professing similarities with the patients. Quick contact appears to be established, if the two parties are not too different.</td>
<td>Both the patient and the professionals are in control. Being the “owner” of the problems, patients are seen as the final problem solvers. Professionals function as guides. The patients’ recognition of the problem is seen as a goal, the professionals’ as a means.</td>
</tr>
<tr>
<td><strong>Awareness of difficult feelings and different points of view in problem solving</strong></td>
<td>Different points of view are seldom detailed, patients and professionals not aware of each other’s ideas in problem solving. Feelings are considered to be ill timed, disturbing problem solving. If patients perceive important problems being ignored they oppose professionals’ suggestions. If professionals are irritated they show reluctance or discuss their feelings with colleagues.</td>
<td>Differences between patients’ and professionals’ perception of problems are diminished and blurred. The relationship loses potential for change. Feelings calling for sympathy are stressed. Good contact tends to become a goal instead of a means. The relationship can end in stagnation, conformity, and cosiness.</td>
<td>Positive and negative feelings of both parties are considered to contain important information directing problem solving. Difficult feelings and different points of view of patients and professionals are revealed in mutual problem assessment. Patients and professionals get access to the potential for change in different points of view.</td>
</tr>
<tr>
<td><strong>Quality of knowledge achieved as the basis of problem solving</strong></td>
<td>Knowledge is delimited to areas found important by professionals. Physical aspects are predominant. Professionals’ hypotheses of difficulties perceived by patients in living with diabetes remain unverified. The patients’ unexpected responses to illness are unknown.</td>
<td>Professionals tend to overestimate similarities between the patients and themselves. They rely on impressions instead of verifying hypotheses of patients’ responses to illness. The true character of problems is blurred, causing a risk of pseudo understanding.</td>
<td>The patients’ knowledge about own difficulties in living with diabetes is valued. Patients and professionals hypotheses of each other’s points of view are verified through mutuality. Knowledge of the patients’ lived difficulties is co-created.</td>
</tr>
</tbody>
</table>
3) the beginnings of *I-You-sorted mutuality*. The relationships were named according to their approach to I-you-boundaries in relational problem solving. They differed in: a) scope of problem solving, b) roles assigned to the two parties, c) awareness of potential for change inherent in difficult feelings and different points of view and d) knowledge achieved and used as a basis of problem solving (Figure 4.2). The three relationships appeared to be more or less conscious patterns formed by expectations about what would and could take place in the approach to the difficulties lived with diabetes. Relationships were thus decisive for the degree to which the potential for change in difficult feelings and different points of view was exploited in relational problem solving. In the following we will detail the three types of relationship

**I-you-distant provider-dominance**

I-you distant provider dominance was characterised by simplification and avoidance. Based on the provider perspective and a narrow scope of disease related problems, a distance between patients and professionals was appropriate in I-you distant provider dominance and professionals appeared to avoid awareness of difficult feelings and different points of view.

In the I-you distant relationships, nurses tended to ask questions which were not real questions, as the nurses already had the correct answers to these questions. The answers comprised rules or general knowledge about diabetes and its best treatment and the purpose of asking these questions appeared to be to test whether patients also knew the answers and if not to teach them. This happened several times in dyad 2 during the first conversation. When the nurse found out that the patient appeared to be satisfied with too high a level of blood glucoses after meals, she wanted to test whether the patient knew what was recommended and thus asked: “What did they say yesterday?” (during diabetes education). When the patient was not quite sure, the nurse repeated the correct answer that the recommended level was 8-10 after meals and then explained the risk of late complications as a consequence of too high a level of blood glucoses.

Perceiving that a narrow perspective was being taken of their situation tended to reduce patients’ expectations and use of professionals. The patient from dyad A10, a 43 year-old woman with Type 1 diabetes expressed it this way:

*Patient:* They can come up with some good ideas. Suggest that I might take that much insulin. But I can’t use them for much else.
Patients experienced that the recommendations of professionals were based on fixed rules rather than knowledge about their specific situation and the experiences they had. This caused anger as expressed by the patient in dyad 11:

Well they don’t want to know. It is the same with all hospitals. Very few listen to the patients’ experience. It is not just me saying that. This goes for everybody in my ward. And we are cross about it, especially when we have had diabetes for many years.

Though professionals might be nice and friendly, patients perceived this distance as a lack of interest in and knowledge about them as persons and this was expressed by the patient in dyad A8:

So, you know, I think they flick through the pages in that thing (the journal). It seemed a bit like it was just something they had to get over and done with.

The scope of problem solving in the provider-dominated relationship was implicitly decided by the professionals and consisted of disease-oriented problems or problems typical for the patient group. The professionals were in charge and expected to be the sole investigators for finding solutions to problems. When problems were investigated and solutions found, patients were expected to follow the professionals’ suggestions. Feelings were implicitly considered to be ill-timed and to disturb problem solving. They appeared, nevertheless, in the form of patient resistance or despondency and professional pressure or reluctance. Different points of view were seldom discussed or explored. The basis of problem solving was not knowledge about person-specific difficulties in living with diabetes.

I-you-blurred sympathy

I-you blurred sympathy appeared to be established spontaneously when professionals became aware of difficult feelings and different points of view during problem solving, which caused a tension they apparently had difficulties tolerating. A tendency to overestimate the resemblances and underestimate the differences between the patient and themselves appeared to be used in an attempt to neutralise this tension. This tendency, however, appeared to blur not only the true difficulties perceived by patients but also the boundaries between patient and professional.
A relationship, which initially appeared to be provider-dominated in dyad A3, changed when the patient, a young man of 18, told the nurse that he had been "toying" with the idea of suicide:

Patient:  *It is bloody hard. Then I can feel really unhappy. Then you do something stupid and think of something stupid and such like.*

Nurse:  *But we all do that. I do it when I lose my head, right? Do some things which I realise afterwards are completely stupid, right?"

By signalling that the difficulty had been recognized and that she herself had thought of and even experienced it, the nurse somehow neutralised the experience. The tension which had been created by the patient sharing this confidence was thereby dissipated.

In the I-you-blurred relationship professionals had a tendency to exaggerate the number of similarities between patients and themselves by inferring an illusory degree of similarity based on a few actual similarities. This was apparent several times in the study, as in this instance where the younger nurse in dyad A10 herself discovered that she had inferred too many similarities:

*Once her daughter arrived and then, I think, I must have looked completely baffled because she was a big girl of sixteen and I had all the time felt as if we were very much on the same wavelength, in age as in everything else.*

Part of the professionals’ understanding of the patient's situation could become a kind of pseudo understanding if elements from the professionals’ own world got mixed up with the general picture. Here the boundaries between the two parties became blurred and professionals unknowingly risked assessing the patient's possibilities based on their own values and situations.

This was evident in dyad A1 in which the nurse assessed the patient's possibility for exercising every day, based on her own situation:

Nurse:  *He...knew very well that he didn't get as much (exercise) as he really should, but he did have two small children and found it difficult to get out, and things like that.*

*Yes, but I understood him very well because I've got small children myself. I know how difficult fitting it in is - if he wanted to attend classes of some kind. It is almost impossible, or at least very difficult.*
When similarities and agreement were nurtured, the patient and the professional appeared to feel comfortable in each other's company. Good contact could hereby become an end in itself and impede professionals in helping patients to actively achieve a positive change. Both patients and professionals instead settled for contentment and the relationship seemed satisfactory to patient, professional and outsiders.

When professionals did not actively seek out differences and particularities in I-you-blurred sympathy but instead only looked for what was expected based on their own world of ideas, they did not obtain any unexpected knowledge. The nurse in the following example made assumptions in her questions which showed that she expected the patient's everyday life to resemble what she knew from her own life. Her questions therefore did not invite the patient to present anything that differed from her assumptions:

**Nurse:** Do you have children yourself?

**Patient:** Yes, I've got two small boys.

**Nurse:** And your days are very much alike I imagine, when you've got children and such.

**Patient:** Yeah.... well there is a lot......it does go very much by a certain rhythm I suppose. But....

**Nurse:** Yes I know that so very well myself. It's not just like that.....You get up and, um you also eat at the ordinary times.

**Patient:** Yes....

**Nurse:** Well, it has to be like that.

When difference and disagreement were overlooked or avoided like this the field of tension between patient and professional would be invalidated and the potential for change in the relationship reduced. That a relationship, which was characterised by sympathy, did not influence the patient's situation was apparent in the following statement made by the patient from dyad A1 at an interview five months after discharge from hospital. The patient said:

*Ann (the nurse) could talk to me about many things. We have really talked about many different things, but in relation to my treatment it hasn't made any difference. In my own way of approaching the illness and coping with the fact that I've got this illness nothing has happened.*

The professionals’ tendency to make use of sympathy to compensate for and balance the consequences of I-you distant dominance was especially noticeable when patients reacted angrily to the use of power or narrow interests. Nurses picking up the pieces after ward rounds was even an example of sympathy being systematized. Sympathy was thus used as a way of “patching
up” the weaknesses of the system, preserving contact between patients and professionals and ensuring that patients did not leave the system feeling anger or despair.

The scope of the I-you-blurred relationship appeared to be unfocused, diffuse and non-delimited. Indistinct roles were assigned to patients and professionals. Professionals were emotionally involved and sensitive to different points of view and difficult feelings but tended to minimise the tension by accentuating similarities to their own experience. Professionals tended to overestimate the shared experience and similarities between patients and themselves. Boundaries between them were thus blurred and it was difficult to exploit the potential for change in differences between patients and professionals. The intention to maintain contact appeared to be a goal instead of a means. Often contact was established quickly with the two parties feeling that they were on the same wavelength. However, if the two parties were too different, contact failed to be established. Unclear decisions seemed to be made and the relationship faced the pitfall of ending in stagnation, conformity, and cosiness. Professional discussions with colleagues about patients’ assumed difficulties appeared to end in unverified hypotheses and tended to increase rather than decrease the barriers to talking with patients about these difficulties. When they relied on unverified hypotheses about person-specific difficulties, professionals were at risk of basing problem solving on pseudo understanding.

I-you-sorted mutuality

I-you-sorted mutuality appeared in two cases in which professionals were apparently aware of the patients’ difficult feelings related to a problem and able to approach them in such a way that the tension seemed to be reduced to a tolerable level.

In one of these dyads (dyad 10) the beginnings of I-you sorted mutuality appeared to be established during a conversation which took place between the patient and the doctor and was witnessed by the nurse one day during ward rounds. The patient commented on the conversation, saying that it had given her "something to think about", while the nurse described it as "what benefited the patient most during the entire admission". The conversation was recounted in the words of the nurse as follows:

*She was just sitting there, crying and crying. She couldn't cope even if she did what we said. She couldn't cope with work. She couldn't, she couldn't, she couldn't.... Then he simply got angry with her: “Now he did not want to hear any more about what she couldn't do. That was a lot of nonsense. There was only one thing wrong with her, and that was that she blamed everything on her diabetes.*
Here the doctor gave vent to his feelings by getting irritated "he had had enough..." and he expressed his thoughts by telling the patient that she had attributed too much negative value to her diabetes by "blaming it .....for everything".

The nurse made some important comments on this conversation, which revealed that she was aware that a relationship with certain qualities had been established. Though they had shown their disagreement during the conversation, she emphasized: “All three of us could laugh about it afterwards”. By remarking that “I did not have to go in and pick up the pieces afterwards” she accentuated the fact that traditional ways of compensating for tensions, which apparently usually take place, had not been necessary in this relationship.

The patient was apparently now assigned a role in which it was she who had to be active and reappraise her stand on diabetes. “Nothing much was said about it afterwards. The patient needed time to ‘digest it’”. This appeared to be something which took place when the patient was alone. “The patient came back a few days later and said that she had thought about it and realized that it was true”.

The patient’s comments on the conversation in a later interview showed that she acknowledged that the doctor’s approach to her had given her something to think about, which she described as follows:

I have also experienced something else there, that doctor, I experienced him differently. He saw me more like a whole person, not just the diabetes. It gives you something to think about. Because he said, ‘Now don’t blame everything on the diabetes. Other things have happened in your life. You have started a new job and such like, right?’ and this gave me something to think about because I have known deep down that this was part of it, it had something to do with me feeling absolutely awful

The patient in dyad 10 was evidently able to cope with and profit from the direct way in which the doctor expressed his assumptions about her reaction to diabetes. This is also clear from a fact emphasized by the nurse that, “the patient asked afterwards to see this doctor every time in the out-patient clinic.”

I–you–sorted relationships explicitly addressed what the two parties assessed as currently being important and difficult for the patient. Patients and professionals were in dynamic interaction. The patients were seen as the final problem solvers while the professionals functioned
as guides. The positive and negative feelings of both parties were considered to contain important information, which was used in reasoning. Difficult feelings and different points of view between the two parties’ were revealed and legitimised, and their potential for change was used. The patients’ knowledge of and stand on their specific difficulties in living with diabetes were given high priority.

**Discussion**

The three relationships appeared to constitute very different frameworks for investigating and solving person-specific difficulties in living with diabetes. Both the distance between patient and professional boundaries in I-you distant provider dominance and the blurred boundaries in I-you blurred sympathy apparently prevented patients and professionals from creating a clear picture of these difficulties. This clear picture only occurred in I-you sorted mutuality, which, however, was seen only rarely.

Part of the I-you sorted relationship appeared to be sorting out and signalling who the owner of the problem was and legitimising the fact that difficult feelings and different points of view would arise when the problem was approached openly in conversations. Professionals thus displayed a readiness to talk about how they perceived the patient’s way of handling problems related to diabetes. In the I-you distant and I-you blurred relationships, patients and professionals preferred to express difficult feelings and different points of view to other people - patients with other patients and professionals with colleagues - instead of expressing and using them in each other’s company.

The importance of using one’s power as a health professional has been stressed by Thorne\(^8\) who points to the difference between using *power with* instead of *power over* the patient. That power differences in relationships are indeed inevitable has also been argued by the philosopher Løgstrup in his power analysis\(^15\), which has been further articulated and transferred into a nursing context by Martinsen\(^16\-18\). Løgstrup stresses that an *ethical demand* exists to use our power to the best advantage for the other. How to answer this ethical demand must be decided according to the situation. Løgstrup in addition stresses that situations always have unique as well as typical features. With regard to the typical features we are able to make rules to follow, while in terms of the unique features we have to make our own judgment of the situation.

When considering the literature on empowerment, I see a danger in health care of mistaking empowerment with consumerism, with a tendency to see the consumer as always being
right\textsuperscript{19}. To avoid this danger we should acknowledge Løgstrup’s point that the ethical demand is silent and is therefore not necessarily identical to the desire expressed by patients\textsuperscript{15} p. 21:

\textit{If it were merely a matter of fulfilling the other person’s expectations and granting his or her wishes, our association would mean nothing less than – irresponsibly – making oneself the tool of the other person. Our mutual relations would no longer present any challenge but would consist merely in reciprocal flattery.}

Clinical research has shown that patients appreciate true awareness and do not necessarily find it important to be pleased by professionals. Paterson thus found that the very few professionals who practised empowerment were not necessarily perceived as being \textit{“warm and tender”}\textsuperscript{2}. Patients more often perceived them as being \textit{“willing to really hear”} them.

Our study indicates that an imbalance of power between patients and professionals is not taken into account. This is evident from the patients’ experience of not being listened to and their point that being poorly regulated gave them the feeling that professionals perceived their experience as being a \textit{wrong experience}. Blumer’s proposal that people’s acts are self-constructed, regardless of whether they are successful or unsuccessful, is relevant in this respect\textsuperscript{20}, p.64:

\textit{The fact that the human act is self-directed or built up means in no sense that the actor necessarily exercises excellence in its construction. Indeed, he may do a very poor job in constructing his act. He may fail to note things of which he should be aware, he may misinterpret things that he notes, he may exercise poor judgment, he may be faulty in mapping out prospective lines of conduct, and he may be half-hearted in contending with recalcitrant dispositions. Such deficiencies in the construction of his acts do not belie the fact that his acts are still constructed by him out of what he takes into account.”}

If we want to help people change acts that we judge to be unsuccessful, we therefore need to acknowledge that these acts are constructed and know how they have been constructed.

A tendency to establish equality between nurses and patients through \textit{I-you blurred sympathy} was seen as a spontaneous reaction rather than a professional one, which also was argued by Briant\textsuperscript{21}. As this tendency appeared to remove the potential for change from relationships, it
seems important to find reasons for it. A study of nurses’ responses to patient anger performed by Smith et.al concluded that nurses who perceived patient anger as posing a high threat to self, managed the threat by disconnecting with the angry patient. Those who perceived the threat to self as low or controllable managed by connecting with the angry patient. I-you sorted relationships appeared to be frameworks for sorting out questions such as ‘Who is the owner of the problem?’, ‘Who is the owner of specific points of view?’ and ‘Who is the owner of a specific difficult feeling?’. In this way I-you sorted relationships appeared to reduce the threat perceived to self in our study and thus helped professionals to act in a helpful way.

The fact that I-you sorted relationships, despite obvious advantages, were rarely seen in our study gives reason to consider the conditions needed to establish this kind of relationship. Many professionals are probably not comfortable with expressing their assumptions directly to patients and having limited time for follow up. Doing so may in addition frighten many patients and have the opposite effect to that intended. Ways of sorting between patients’ and professionals’ points of view in a non-threatening way and inviting the expression of difficult feelings in busy clinical practice have as yet hardly been developed at all.

**Implications for practice and research**

Health care providers can be recommended to be critically aware of the relationships they establish with patients. Relationships constitute an opportunity to mirror the lived paradigms of health providers and offer insight into the degree of consistency between stated and the lived paradigms. An I-you-sorted relationship is concluded to be a necessary framework for effective relational problem solving and ways of achieving this framework need to be developed and implemented in chronic care.

**Acknowledgements**

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This article adds

**Relational potential for change**

Patients and professionals exploit the potential for change in very limited degree in: *I-you distant provider dominance* and a compensatory *I-you blurred sympathy*. The beginnings of *I-you sorted mutuality* are seldom seen.

Relationships differ on:
   a) **scope** of problem solving  
   b) **roles** assigned to the two parties  
   c) way of **handling tension** related to difficult feelings and different points of view  
   d) **quality of knowledge** achieved as the basis of problem solving

It is suggested that **pattern interruption** be achieved by establishing *I-you sorted relationships*
Reference list


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Chapter 5

Model of person-specific reflection
Paths and barriers for mutuality in difficult problem solving

Vibeke Zoffmann RN MPH, Ingegerd Harder RN Ph.D and Marit Kirkevold RN EdD
Abstract

Mutual reflection in patient-provider relationships has convincingly been linked with enhanced problem solving. Yet serious difficulties appear to exist in achieving mutuality in clinical practice. In diabetes care we hypothesise that a lack of mutuality means that patient and professional skills are poorly exploited in the enhancement of patient self-management. Yet this connection has hardly been explored, especially in difficult problem solving. Interactions between diabetes patients with poor glycaemic control and health care providers were studied in eleven dyads using grounded theory methodology. Variations in approach to communicative paths and barriers were conceptualised and assembled in a person-specific reflection model specifying 1-5 zones of focusing and 0-IV levels of deepening situational reflection. Mutuality appeared to require zone-5 focusing and level III-IV situational reflection. Data are from the initial phase of a 4-phase research program into innovation of methods in relational problem solving conducted at a Danish university hospital between 1996 and 2004.

Keywords: problem solving, diabetes, communication, reflection, grounded theory.
**Introduction**

Although comprehensive research has demonstrated that mutuality rather than paternalism supports people in developing self-management skills for chronic illness, research in clinical practice shows that professionals still deliver care characterised by paternalism.

Mutuality has been defined as the midpoint between paternalism and autonomy and is associated with negotiation in patient-provider communication. It enhances interaction, accountability and effectiveness in problem solving and seems to be suitable in chronic care for conditions such as diabetes, in the process of empowering patients to self-management of the illness. Williams et al. demonstrated a correlation between the autonomy support patients perceived from professionals and patients’ possibility of improving glycaemic control. Research, however, has revealed difficulties in accomplishing mutuality in clinical practice even in the care of diabetes patients with good glycaemic control.

Different approaches, such as empowerment, self-determination and coping-skills training, invite the owner of a problem to participate in decision-making and problem solving instead of just complying with decisions made by professionals. The effectiveness of these alternatives has been supported by recent research on goal attainment in college students. Sheldon and Elliot showed that college students who set goals consistent with their core values and personal development interests improved goal attainment and reaped greater well-being benefits from their attainment.

Living with poor glycaemic control increases the risk for diabetes patients of developing disabling complications affecting the eyes, kidneys, and nerves. These complications are seen in considerable numbers of diabetes patients and according to research up to 50% still do not achieve the degree of glycaemic control known to be ideal for preventing these complications. Attempts to improve regulation often fail or result only in a transitory decrease in blood sugar, leaving patients and professionals disappointed at seeing considerable effort wasted and patients still having a high risk of long-term complications. In an interrelated study we identified a life versus disease conflict, which disempowered patients and professionals in difficult diabetes care, and suggested that a rarely seen mutuality-expecting approach to problem solving might be one key to finding a solution. We hypothesise that mutuality will require an innovation of methods in clinical judgment, with particular emphasis on mutual problem clarification. To explore this further, the current study aims at detailing how patients and professionals in difficult diabetes care gain...
insight into and influence each other’s reflections on the patients’ difficulties in living with diabetes.

**Method**

The study used grounded theory methodology comprising a symbolic interactionist perspective and a constant comparative method.

**Participants**

Eleven patients and eight nurses from an in-patient unit or day clinic at a Danish university hospital were invited and agreed to participate. Inclusion criteria for patients were: a) age ≥ 18 years, b) diagnosed with diabetes ≥ 1 year and c) admitted because of poor glycaemic control (HbA1c ≥ 8.0%). Nurses were included if they were familiar with traditional diabetes care and had more than 1 year of experience from a specialised diabetes unit. Eight of the patients were aged 18-42 years and had been suffering from Type 1 diabetes for 2 – 25 years (median 9). Three were aged 49-63 years and had been suffering from Type 2 diabetes for 1-4 years. All patients (seven female and four male) with HbA1c 8.4 – 18.0 had attended individual or group based diabetes education as conventionally offered by the hospital. Eight nurses with 1-17 years of experience in diabetes care (median 4) participated as “contact nurses”, responsible for care of the patient.

**Sampling procedure**

Despite poor metabolic control, the first patient included had a high level of resources for the self-management of diabetes. This patient was highly critical of the approach to care adopted by health care professionals. Following the constant comparison principle of grounded theory, this case generated a hypothesis that interactions between professionals and patients with an imbalance between poorly regulated diabetes on the one hand and high levels of self-management resources on the other would reveal how the power of patients and health care professionals was perhaps being used inappropriately. In order to investigate and contrast processes related to this imbalance, subsequent patients were theoretically sampled to ensure a variation in levels of self-management resources. Seven patients were judged to have high levels of self-management resources. Four patients appeared to have low levels of self-management resources. These assessments were based on information in the patients’ medical records. Further investigation during data collection verified or modified this first impression, leading to the sample included in this study.
Table 5.1. Characteristics of patient-nurse dyads in grounded theory study.

<table>
<thead>
<tr>
<th>Dyad number</th>
<th>Sex</th>
<th>Age (years)</th>
<th>Type of diabetes</th>
<th>Illness duration (y)</th>
<th>Late complications</th>
<th>Day and night (D&amp;N)/day unit (D)</th>
<th>Type of treatment</th>
<th>Nurse experience in diabetes care</th>
<th>Conversation with colleague</th>
<th>HbA1c at admittance</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>M</td>
<td>29</td>
<td>1</td>
<td>Yes</td>
<td>D</td>
<td>Insulin</td>
<td>8/7</td>
<td>Physician</td>
<td>9.9</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>F</td>
<td>54</td>
<td>1</td>
<td>No</td>
<td>D</td>
<td>Insulin</td>
<td>36/17</td>
<td>Dietician</td>
<td>8.4</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>M</td>
<td>18</td>
<td>1</td>
<td>No</td>
<td>D&amp;N</td>
<td>Insulin</td>
<td>4/2</td>
<td>District nurse</td>
<td>18.0</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>M</td>
<td>63</td>
<td>2</td>
<td>Yes</td>
<td>D&amp;N</td>
<td>Tablets to insulin</td>
<td>12/1</td>
<td>Nurse</td>
<td>9.0</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>F</td>
<td>34</td>
<td>1</td>
<td>Yes</td>
<td>D&amp;N</td>
<td>Insulin</td>
<td>11/4</td>
<td>Not taped</td>
<td>9.3</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>F</td>
<td>42</td>
<td>1</td>
<td>No</td>
<td>D</td>
<td>Insulin</td>
<td>8/7</td>
<td>Dietician</td>
<td>11.0</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>F</td>
<td>49</td>
<td>2</td>
<td>No</td>
<td>D</td>
<td>Diet</td>
<td>36/17</td>
<td>Dietician</td>
<td>8.5</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>F</td>
<td>55</td>
<td>2</td>
<td>No</td>
<td>D</td>
<td>Tablet</td>
<td>16/15</td>
<td>Dietician</td>
<td>10.7</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>M</td>
<td>20</td>
<td>1</td>
<td>2½</td>
<td>No</td>
<td>D&amp;N</td>
<td>3/3</td>
<td>Team</td>
<td>11.0</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>F</td>
<td>43</td>
<td>1</td>
<td>No</td>
<td>D</td>
<td>Insulin</td>
<td>5/4</td>
<td>Dietician</td>
<td>11.0</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>F</td>
<td>32</td>
<td>1</td>
<td>Yes</td>
<td>D&amp;N</td>
<td>Insulin</td>
<td>3/3</td>
<td>Nurse</td>
<td>12.0</td>
<td></td>
</tr>
</tbody>
</table>

**Data sources**

As the primary sources, two patient-nurse conversations were taped from each dyad, one at the beginning and one at the end of the hospital stay. They documented what was discussed, planned, accomplished and evaluated. In addition, each nurse was asked to tape a discussion with a doctor, dietician or another nurse from the team, which she considered to be important in appraising the patient’s situation. These conversations revealed observations, feelings, concerns and ideas exchanged internally in the diabetes team when patients were not present. In each case, all three conversations were listened to before semi-structured interviews were conducted, first with the patients after discharge and then with the nurse, revealing the experiences, considerations and feelings of both parties with regard to the hospital stay. Finally an interview with the patient half a year later revealed how they assessed the outcome of the hospital stay, taking into consideration changes accomplished or still unaccomplished in daily life with the illness.

**Analysis**

The interviews and conversations were saved and processed as sound files supported by the Qualitative Media Analyser (a computer program providing simultaneous access to the original auditory details of the data and connected transcriptions and notes during coding)\(^{20}\). Constant comparative analysis, as recommended by grounded theory\(^{16-18}\), was performed in a four-step inductive analysis. Initial open coding was performed on each conversation or interview soon after it took place. Through a combination of listening and writing notes, in vivo codes were discovered,
which provided ideas for the tentative advancement of more abstract codes. Secondly, a critical comparison focused on the most solid and ‘insisting’ categories, which were now supported by transcriptions of the coded data. This was used to specify the content and further the advancement of lasting categories and sub-categories. Step two ended when saturation was reached and ideas for tentative links between categories appeared to emerge. All data sources were compared at the third step, which made use of drawings in the process of exploring and verifying theoretical links between concepts. The fourth step of analysis continued throughout the process of writing, identifying a core category of co-creating person-specific knowledge and connecting it with most of the other categories. At each step, returns might be made to former steps in order to test ‘fit’, ‘work’, ‘relevance’ and ‘modifiability’.

The process of co-creating person-specific knowledge, was completed most clearly in dyad 4 and 10, where barriers were overcome through three processes of focusing, deepening situational reflection and bridging life and disease. For example, focusing was revealed through an analysis of data from the first patient which showed that person-specific difficulties mentioned by patients and professionals in nurse-colleague conversations or in interviews, were seldom addressed in patient-professional communication. Further comparison across dyads revealed great variations in focus. These variations were expressed in a figure with a central zone 5 representing clearly stated person-specific difficulties and increasingly defocused content in zone 4, 3, 2 and 1 (Figure 5.1). Further comparison revealed deepening situational reflection as another process. Degrees of reflection were differentiated into four levels and represented by a funnel. Level III was crucial for bridging life and disease and guiding a patient to further independent reflection at level IV.

Validity

Validity was considered at several levels. We acknowledged Glaser’s contention that a researcher’s assumptions can be helpful in developing alertness or sensitivity to what is going on but can also inhibit the researcher in discovering a new theoretical formulation through emergence. To increase critical awareness of our assumptions and benefit from them to sharpen the focus of the study, we expressed our ideas on vital issues in mutual decision-making prior to the study. In order to provide a reliable impression of the care delivered, conversations were recorded at strategic times at the start and end of the hospital stay. Barriers to taking action were revealed by including data about reflections shared by professionals while planning the care. It was also considered that better understanding of how patients judged the care would be achieved by interviewing them twice at
different intervals after discharge. Knowing that the character of a conversation might change if patients and professionals were distracted by a researcher being present, we chose to ask permission for the interaction between patient and nurse to be taped without the researcher being present. The aim was to capture a reliable image of the usual care in daily practice by asking nurses to ‘do as usual’. If they wanted to be especially competent, it was suggested that they be ‘especially competent in doing as usual’.

**Ethics**

Informed consent was obtained from all participants, who were informed that their statements would be handled anonymously and confidentially. The protocol was prepared in accordance with the Helsinki declaration and approved by the ethics committee of Aarhus County.

**Findings**

Analysis identified a core category of problem assessment, which we termed *co-creating person-specific knowledge*. Around this category, a conceptual pattern, essential to the quality and outcome of clinical judgement, consisted of three processes; *Focusing on person-specific difficulties, bridging life and disease* and *deepening situational reflection* (Figure 5.1).

The pattern is represented in a model of person-specific reflection which has brought together separate elements and represents the essential patterns of each process: 1) Zones of focusing situated on a surface around a central zone 5, representing the degree of focus on the true difficulties currently experienced by a specific person in living with diabetes. 2) The vertical axis represents the barrier that exists to bridging life and disease in the approach to problems. 3) The zone 5 circle represents a turning point from which reflection can move towards a general understanding of the problems based on non-situational reflection in one direction (upwards) and towards a person-specific understanding based on situational reflection in the other (downwards). 4) The four levels of situational reflection represent degrees of patient participation: I. being observed, II. delivering information, III. mutual reflection with a professional and IV. independent reflection guided by professionals. Mutual and independent reflection at level III and IV respectively appeared to enhance problem solving through *co-creation of person-specific knowledge*. 
Figure 5.1. **Model of person-specific reflection**  
*A grounded theory developed in difficult diabetes care*

<table>
<thead>
<tr>
<th>Focusing zones 1-5.</th>
<th>1: Focusing with unspecific subjects.</th>
<th>4: Focusing on subjects related to, the patient but currently not difficult.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2: Focusing on general health related subjects.</td>
<td>5: Focusing on subjects currently difficult for the patient.</td>
</tr>
<tr>
<td></td>
<td>3: Focusing on subjects of general significance for the patient group.</td>
<td></td>
</tr>
</tbody>
</table>

**Non-situational reflection**

**Disease-oriented dimension**

**Life-oriented dimension**

<table>
<thead>
<tr>
<th>Levels of reflection</th>
<th>Health care professionals’ (HCP) contribution.</th>
<th>Patients’ contribution.</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Have noticed signs of person-specific difficulties, but do not reflect on them in a situational way.</td>
<td>Not aware of HCP’s considerations.</td>
</tr>
<tr>
<td>I</td>
<td>Are reflecting by themselves on observable signs of person-specific difficulties.</td>
<td>Not aware of or engaged in HCP’s reflection.</td>
</tr>
<tr>
<td>II</td>
<td>Are reflecting by themselves on observable and non-observable aspects of person-specific difficulties. Gather information from the patient, but do not invite the patient’s judgement on these difficulties. Hypotheses unverified.</td>
<td>Are contributing information but not engaged in HCP’s reflection or asked to verify or judge the assumed difficulties.</td>
</tr>
<tr>
<td>III</td>
<td>Are engaged in mutual reflection with the patient, exchanging thoughts and ideas of difficulties related to the patient’s responses to living with the illness. Hypotheses verified and knowledge of person-specific difficulties co-created; importance, causes, meanings and possible solutions clarified.</td>
<td>Are engaged in mutual reflection with HCP, verifying and exchanging thoughts and ideas of difficulties related to living with the illness. Are co-creating knowledge of importance, causes, meanings and possible solutions to the difficulties.</td>
</tr>
<tr>
<td>IV</td>
<td>Though not participating in reflection themselves, HCP motivate patients to reflect by e.g. applying value clarifying questions, reframing or pointing at possible inconsistency in patient response to illness.</td>
<td>Are reflecting independently, reassessing their own responses to and stand on their specific difficulties. Autonomous motivation may facilitate self-determined change.</td>
</tr>
</tbody>
</table>
Focusing zones 1-5
Inconsistencies appeared to exist between the difficulties discussed during patient-professional communication and the subjects mentioned in interviews or discussions between nurses and their colleagues.

Focused zone-5 communication about current problems rarely seemed to take place. Contributory factors seemed to be not only the complexity of the illness weighed against the limited time available but also resistance and reluctance to address difficult matters. For instance, patients seldom told professionals what was really difficult for them and professionals seldom told patients what they regarded as being most difficult for the patient. Patient resistance to focusing on specific difficult matters was perceived by patients and expressed as follows by the patient in dyad 1:

“I think a lot of people feel that way, that we know as patients we should say how we feel and what we think and how we really are and so on but it is not easy, is it? People don’t find it easy to open up and just talk about their feelings and how it all fits together inside. ...The nurses’ job would be much easier if the patients could push a button and then just talk.”

Professionals also had difficulty focusing on difficult matters and were sometimes aware that they were even using patient resistance as an excuse for avoiding difficult matters, like the nurse in dyad 11:

The signals, that we should not get too close to her – “only so far and no further” became a bit of an excuse for not going into it in any depth.

On other occasions, professionals were aware that they had become part of a communicative pattern they were not able to change. One doctor explained to the nurse in dyad 1:

“You become involved in such theoretical discussions, which means that you lose sight of the real point. It is very interesting because he knows a lot about the hospital world and so on. Then you end up discussing some detail, which makes it difficult.”

A lack of selection could also contribute to de-focused communication, if patient and professional identified several more or less well-defined problems but did not take a stand concerning what to accomplish during the hospital stay.

Furthermore, imprecise invitations from professionals meant that the subject of communication might differ from what was intended. This discrepancy was frequently confirmed
when professional invitations were compared with their intentions as revealed in conversations with other professionals or in interviews. Communication seemed to circle around the current difficulties in zone 5 because invitations de-focused communication away from difficult subjects by addressing the more general concerns in the outer zones.

The importance of addressing the desired zone directly was emphasized by the fact that communication initially situated in one zone tended to remain there for quite a while and shifts to another zone appeared to be difficult. Communication in the “wrong” zone thus delayed communication in a more relevant zone. In particular, the two zones closest to zone 5 were often unintentionally addressed in attempts to address person-specific problems. This was illustrated by the following conversation between the nurse and the patient from dyad 11, where an attempt to discuss loneliness (perceived as a current problem) ended up with a long talk about four cockatoos. The nurse twice invited the patient to talk about loneliness. The first invitation, “Do you live alone?” was understood as an invitation to talk about whether she could afford to live in her new house, while the second invitation, “You don’t have any pets or anything?” was taken literally as a proposal to talk about animals:

Nurse:    Do you live alone?
Patient:  It is a house I bought very cheap
Nurse:    You don’t have any pets or anything?
Patient:  I have some cockatoos but they are with my mother at the moment. She is looking after them. One of them I inherited from my brother. It is unbelievably old. He said we only had to look after it for a couple of years. We have had it for 14 years now. It must be 23 now. That is a lot. Normally they live for 8 years.
Nurse:    That’s incredible
Patient:  Then I have a pair of young ones as well. And she is much more interested in the old bird than the young one, even if he is a bit dishevelled. He goes on a bit. He puffs himself up when he sees her. Then I have one, who is tame, that’s the old one’s son. He sits with a collar on and thinks the world of himself. He will end up very old as well.

The nurse later confirmed that loneliness was the intended issue. When interviewed, she called attention to this part of the admission interview, describing it as irrelevant but connecting this with the patient’s way of talking and not with her own invitations.
Zone 3 invitations were also common and resulted in communication about general rather than person-specific problems. In the conversation at discharge the nurse in dyad 1 returned to the patient’s criticism from earlier in the hospital stay. She intended to invite the patient to provide more detail:

Nurse: You talked about the social aspect at one time or other – that it was all right that we looked at the blood test and so on, but you said that you thought we didn’t do enough about the social aspect.

This zone 3 invitation to provide detail about a general comment resulted in a 17-minute exchange of opinions about current policy in diabetes care. Then the patient took the initiative to move the communication into zone 5. He did it as follows:

Patient: But let us take my... up to now we have spoken generally..... and if we should give this a fair evaluation then take my situation...

The last two minutes of communication were about the fact that the patient had adjusted his injection technique and acknowledged that the hospital stay had provided time to think about his diabetes.

When communication was situated in zones 4 and 3, it could easily slip even further into subjects more distant from the assumed difficulties, addressing general health subjects in zone 2 or very general subjects in zone 1. This occurred in the above cases. Communication about diabetes policy developed into a discussion about letting parents-to-be choose abortion if an embryo was the ‘wrong’ sex. The talk about the house moved on to a discussion about areas in the city.

Communication in zones 1 and 2 seemed to have the least relevance to clarifying a patient’s problems. In return it appeared to be of shorter duration than communication in zone 3 and 4. The relevance of subjects in the latter zones seemed to be more difficult for patients and professionals to determine.

**Barriers to bridging life and disease**

The process of bridging life and disease also represented a barrier, as patients and professionals frequently showed difficulties in moving from the disease to the life-oriented dimension or in connecting the two. Being mostly disease-oriented and focusing on symptoms, examinations, diagnoses and treatments, professionals’ communicative approach to problem solving mostly
appeared to be ‘stuck’ on the disease specific side, as noticed and expressed by the nurse in dyad 10:

Nurse: We just sat and looked and looked at the glucose levels. We were like completely fixated on them. I think I was getting into a knot with her. We were also very busy then. No, I lost her.

The fact that the vertical axis between life and disease (Figure 5.1) constituted a barrier between the disease-oriented and the life-oriented dimension seemed to be pushed to an extreme in dyad 11. In interviews, the patient used the metaphor “Diabetes is a vermin that you carry around with you,” explaining that she had earlier experienced a serious lack of communication with professionals about the problems she perceived in living with diabetes. “I finally got a depression ... a deep hole with very slippery sides which made it extremely difficult to climb out”. Yet this patient’s behavior indicated that she herself stressed the disease-oriented dimension. She was familiar with and used many technical terms and also negotiated with doctors for more examinations. In a 45-minute conversation at admission she described her history by using pages of disease-specific notes about physical symptoms, examinations and treatment. However, living with diabetes still appeared to be extremely difficult for this patient and in interviews she expressed regret that the team concentrated on the “purely physical....You know, I think that it is a deficiency in the system that you don't talk about psychological things”. The nurse’s awareness of this patient’s ambivalence was evident:

I cannot remember that she mentioned that she had a depression during the admittance interview, but I might be wrong. Then I heard about it at the discharge interview. It might have been an out-stretched hand. Somehow she was able – now that she was on the way out of the door - to open up a bit, open up the backdoor without it having any consequences for her.

Though aware of her own unanswered need for psychological help, this patient seemed to have got stuck in a symptom-examination-treatment circle - a pattern that somehow kept her in the disease-oriented dimension. This patient needed support from professionals in bridging the disease and life dimensions or in making a lateral reversal from the disease-oriented to the life-oriented dimension. This was not accomplished during the hospital stay. One way of bridging life and disease appeared to be to address a patient’s responses to illness.
Deepening situational reflection

Having identified a problem, professionals seemed to face a turning point between making do with non-situational reflection based on general knowledge or expanding it into situational reflection and creating person-specific knowledge.

The knowledge obtained in the two first levels (I-II) of situational reflection was, however, obtained from the professional perspective and was not verified by patients. At level I professionals’ generalised knowledge of the issue identified was supplemented solely with details obtained through observing the patient. They did not know if the patient was reflecting on the same issues or was concerned with other issues. Neither did professionals at level II, who reflected on both observable and non-observable aspects of an issue. Reflection on non-observable aspects required information, which patients were asked to deliver without being invited to share and being generally unaware of professionals’ reflection. In this way patients unknowingly provided information for professionals’ reflection on lack of motivation, lack of responsibility for the illness, assumptions about seeking frequent admission because of loneliness, fear of late complications and unreliable information about eating habits.

Sometimes patients provided a subject for reflection by mentioning a problematic issue. Professionals’ comments on such issues might, however, impede reflection by signifying that they did not attach any importance to the problem or took it for granted. In the following example the patient in dyad 2 admitted that she tended to eat too much when her blood sugar was low. “I am afraid I fill up with too much fuel when my blood sugar is too low. To be honest.” By simply answering: “Well, you are honest” the nurse did not deepen reflection. She did not reach level III and explore how the patient appraised this tendency in daily life.

Not until level III did patients and professionals know about and influence each other’s reflection. At this level professionals and patients were involved in mutual reflection and exchanged perceptions, thoughts, feelings and ideas in order to determine the meaning, the importance, the cause and the possible solutions to difficulties perceived by patients. Knowing each other’s judgments, patients and professionals at this level had the possibility of rejecting, correcting, confirming or supporting each other’s assumptions and exploiting the potential for change in their different skills and points of view.

Other than in reflections on self-measured blood sugar results connected with concrete events in daily life, this level (III) was only reached in two of the dyads. Suffering from painter’s syndrome the patient in dyad 4 remarked on his problem with impaired memory at admission. As
his treatment during the hospital stay was going to be changed from tablets to insulin, the nurse and a colleague discussed how they should take this forgetfulness into account when providing information about precautions related to insulin treatment. They decided to select only the essential information and write it down on a piece of paper. However, knowing his own ability to read messages the patient contributed by asking the nurse to write the information in block capitals, which she did. Their co-created knowledge thus improved the usefulness of the note, which benefited the patient as he remembered it in his pocket when he was out shopping and first experienced symptoms of low blood sugar.

In dyad 10 the patient was open about her difficulties in living with the illness. A doctor deepened reflection to level III by expressing his interpretation of the patient’s response to diabetes. The conversation was witnessed by a nurse who described it as "what benefited the patient most during the entire admission" and recounted it as follows:

She was just sitting there, crying and crying. She couldn't cope even if she did what we said. She couldn't cope with work. She couldn't, she couldn't, she couldn't....

Then the doctor simply got angry with her: “Now he did not want to hear any more about what she couldn't do. That was a lot of nonsense. There was only one thing wrong with her and that was that she blamed everything on her diabetes”.

Expressing his feelings by getting irritated ("he had had enough...") and his thoughts by telling the patient that she had given her diabetes too much negative value, the doctor asked the patient to pay attention to and reconsider her own responses to diabetes. The nurse made some important comments on the conversation:

All three of them could afterwards laugh about it: she did not have to go in and comfort the patient; nothing much was said about it afterwards – “the patient needed ‘time to digest’ it”.

A few days later the patient returned and confirmed the doctor’s view, saying that “it was true”. When alone she had apparently deepened reflection to an independent level IV reflection and thereby achieved self-insight and taken a stand against her current attitude and behaviour. Level IV could only be reached by patients themselves and professionals did not participate in reflection at this level. They did, however, have an important role in motivating patients to start independent reflection, for instance by disclosing their own perception of the patient’s response to a certain problem. While several patients appreciated that the hospital stay gave them time to think about
their diabetes, only the patient mentioned above clearly expressed the view that professionals had given her something to think about.

Together level III and IV reflection resulted in a person-specific knowledge of lived difficulties co-created by patients and professionals instead of the unverified hypotheses seen at level I and II. Hearing the patient commenting on and verifying the doctor’s assumption appeared to be a final confirmation of the correctness of the co-created knowledge.

**Discussion**

The current study aimed at detailing how patient and professional approaches to paths and barriers in problem clarification influenced their ability to use each other’s skills in difficult diabetes care. The core category of co-creating person-specific knowledge through three processes was an important finding and was represented in the model of person-specific reflection. The variation in patient and professional abilities to overcome the barriers inherent in these processes could be satisfactorily explained by the theoretical findings. In addition, the study specified patients’ and professionals’ current approach to such barriers in their attempt to provide a new understanding of difficulties in accomplishing mutuality in clinical practice. Finally, the study suggests a reasonable explanation of why both patients and professionals with a potential for solving difficult problems might fail in relational problem solving.

Bridging life and disease and profiting from professional competence at level III gave patients an increased possibility of combining and acknowledging life and disease-oriented aspects in decisions they were about to make concerning future disease management. The importance of considering not only aspects concerning their own disease, but also aspects concerning their family and work situation in decision-making accords with the idea of developing “balanced self-determinism”

21. Balanced self-determinism describes people who are “able to exercise their rights without denying the rights of others”. If decisions about diabetes were made without taking the life with other people into account, unrealistic plans might be made for never to be carried through by the patient.

The path between mutual reflection at level three and self-dependent reflection at level four adds a cognitive dimension to earlier studies recommending mutuality2 and serves as a path to expanded? consciousness as described by Newman 22.

The core category of **co-creating person specific knowledge of lived difficulties** suggests that evidence based problem solving needs to comprise person-specific knowledge co-
created through situational reflection. Four decades ago, interactive problem solving recommended insight into patient reflection as a way of learning about a patient’s real reasons for acting in a way that appeared problematic from a professional perspective. Knowing these reasons might help professionals understand and accept such actions as non-problematic or provide them with a thorough basis for challenging patients in an autonomy supporting way and making them reconsider and perhaps change their actions. Our findings showed that professionals normally failed to get this insight due to communicative barriers in three different processes: focusing, bridging life and disease, and deepening situational reflection.

The question about the time needed for solving difficult problems was raised in our study and has often been raised in daily practice. As pointed out by Paterson, limited time may impede mutual problem solving. The identification of problems appeared to be particularly time consuming in our study because of the complexity of the illness. On the other hand, we also found that having plenty of time did not necessarily improve the appraisal of problems if professionals were unable to ‘focus’, ‘bridge’ and ‘deepen’ person-specific reflection.

Addressing people’s responses to illness has been broadly recommended in nursing. In the study drawing attention to these responses appeared to be an effective way of bridging life and disease in problem appraisal.

It seems inevitable that professionals with limited situational knowledge at levels 0, I and II try to motivate patients to act on the basis of rules and generalized knowledge. According to self-determination theory, patients can easily perceive such an approach as pressure and thus begin to develop controlled motivation. This type of motivation corresponds with ‘other-determined behavior’ as discussed above and has, in a follow-up study, been connected with higher blood glucose. The fact that a focused and bridged approach to problem solving was seldom developed into person-specific reflection at levels III and IV is consistent with comprehensive research findings showing that professionals mostly treat patients according to a rule based approach and expect them to comply with professional solutions to problems.

Posing problems adequately (meaning both verifying that an issue is a problem to the patient and agreeing on a name for it) seemed to give these problems the necessary substance to become objects of mutual reflection between patient and provider. The ability to ‘pose’ a problem is mentioned as a necessary part of people’s life skills. Our findings support the importance of ‘posing problems’ in order to avoid talking past each other or addressing too diffuse a subject in problem solving.
Conclusion and implications for practice

A person-specific reflection model was developed on the basis of eleven dyads specifying paths and barriers to co-creating knowledge of person-specific difficulties in assessing difficult problems with diabetes. It could be concluded that activity mostly took place on the disease-oriented side of the vertical axis; that problem-identification was impeded because communication failed to focus on the difficult matters in zone 5; that mutual reflection at level III and independent patient reflection at level IV appeared to enhance problem solving but were seldom achieved. The ineffectiveness of problem solving in difficult diabetes care supported and specified a need for studying the details of patient-provider relationships further as well as for method innovation in order to facilitate mutual problem solving.

Acknowledgements

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This article adds:

Model of person-specific reflection

- Disease oriented approach was common.
- Life-oriented approach was rare.

- Zone-specific invitations.
- Resistance or reluctance against focusing.
- Communication mostly addressed zone 1-4, seldom zone 5.

- Non-situational reflection frequently appeared.
- Situational reflection mostly took place at level I-II. Seldom reached mutuality at level III and independence at level IV.

- Knowledge of person-specific difficulties was seldom co-created.

Consequences for development of GSD

- It is suggested that zone-5 specific communication should be promoted through written invitations in worksheets and situational reflection at level III-IV through dynamic judgment building.

- It is suggested that knowledge of person-specific difficulties should be co-created.
Reference list


Chapter 6

Guided Self-Determination

Development, implementation and clinical significance in one-to-one settings
Adjustment to group settings and measurements for RCT
6.1. Introduction

An intervention was conducted on the basis of findings from three inter-related grounded theory studies (Chapters 3-5) revealing barriers to effective relational problem solving between patients and professionals (Figure 6.1). These findings supported the overall hypothesis that the methods used in relational problem solving were inconsistent with empowerment and lacked the necessary apparatus for exploiting the potential of patients and professionals.

The grounded theory findings, however, also showed possibilities for developing a consistent and more promising method and thus formed the basis for Guided Self-Determination (GSD) (Figure 6.2; Table 6.1). GSD was designed to guide diabetes patients and professionals through mutual problem solving. It is hypothesised that differences between the two parties’ points of view represent a potential for change, which it would be advantageous to emphasize and use in the process of promoting the changes desired.

There were four goals in using GSD in the intervention. Firstly, the scope of problem solving should include difficulties in developing life skills with diabetes (Chapter 3). Secondly, pattern interruption of the patient-provider interaction was aimed at by establishing I-you sorted relationships (Chapter 4). Thirdly, zone 5 specific communication was promoted through written invitations on worksheets. Lastly, nurses aimed at co-creating knowledge of person-specific difficulties together with patients through situational reflection at level III-IV (Chapter 5).

The aim of this chapter is to detail the development and implementation of GSD and present the results of an intervention study testing its clinical significance when used in a one-to-one setting in clinical practice. At the end of the chapter the further refinement of GSD and its adjustment to group-settings will be described in addition to a selection of measurements for testing its effect in an RCT.
Figure 6.1. EFFECTIVE FACTORS IDENTIFIED IN GROUNDED THEORY FINDINGS:

**Keeping life and disease apart**

*Life versus disease conflict* within and between patients and professionals.

- Professional *pressure* - Professional *reluctance*.
- Patient *resistance* - Patient *despondence*.

*Compliance expecting* approach – Patient having a problem.
*Failure expecting* approach – Patient being a problem.
*Mutuality expecting* approach – Patient being a problem solver.

*Life skills with diabetes* a neglected dimension of patient care.

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**Relational potential for change**

Patients and professionals tend to be trapped in a fixed pattern formed by: *I-you distant provider dominance* and a compensatory *I-you blurred sympathy*. The beginnings of *I-you sorted mutuality* are seldom seen.

Relationships differ on:
- a) **scope** of problem solving
- b) **roles** assigned to the two parties
- c) **way of handling tension** related to difficult feelings and different points of view
- d) **quality of knowledge** achieved as the basis of problem solving

---

**Model of person-specific reflection**

*Disease-oriented* approach.
*LIFE-oriented* approach.

*Zone-specific invitations.*
*Resistance or reluctance to focus.*
Communication mostly addressed *zone 1-4*, seldom *zone 5*.

*Non-situational reflection* frequently appeared.
*Situational reflection* mostly took place at *level I-II*. Seldom reached *mutuality* at *level III* and *independence* at *level IV*.

*Knowledge of person-specific difficulties* was seldom *co-created*.

---

It is suggested that the *scope of problem solving* should include difficulties in developing *life skills with diabetes*.

It is suggested that *pattern interruption be achieved by establishing I-you sorted relationships*.

It is suggested that *zone 5 specific communication be promoted* through written invitations on worksheets and *situational reflection at level III-IV* through dynamic judgment building.

It is suggested that *knowledge of person-specific difficulties should be co-created*.
6.2. Development and implementation of GSD

GSD guided professionals towards consistently using autonomy support during problem solving. Semi-structured GSD worksheets (WS), were filled in by patients before and between conversations (Figure 6.2), (Table 6.1), (Appendix D). Patients were thus guided through a process of exploring difficulties in living with diabetes systematically and creatively by means of words and drawings. This made them prepared to identify crucial problems and express their thoughts and feelings in a process of developing internally motivated self-management of diabetes. Patients and professionals prepared independent lists of issues they perceived to be difficult in the patient’s life with diabetes and subsequently agreed to focus on 1-3 problems (WS 1b).

6.2.1. Reasons to take the step from oral to written communication

The step from oral to written communication by developing worksheets was based on grounded theory findings, as the following incident from dyad A10 illustrates.

A conversation, which took place between the patient and a doctor during rounds, was recounted in the words of the nurse. The doctor invited the patient to focus on one of her responses to diabetes, which he thought influenced her negatively. His invitation was phrased as a statement: “The only thing that is wrong with you is that you blame your diabetes for everything”.

At the core of the doctor’s statement was a general tendency: sometimes people wrongly blame diabetes for something which is actually caused by other life conditions. The statement was probably based on his perception of the patient, which had convinced him that this was what had happened in her case. According to the nurse, the patient at first replied that he was not the one who had diabetes, but after a long talk she was able to laugh about it together with the doctor and she afterwards emphasized that the doctor had given her something to think about.

The patient in dyad A10 benefited from the direct approach chosen by the doctor. Other patients might, however, become scared or angry and this would result in the comment doing more damage than good. The response to diabetes addressed in the doctor’s statement was therefore transformed into an unfinished sentence in worksheet 2c, (Appendix D), as this was judged in general to be more suitable for patients.

The unfinished sentence in worksheet 2c functions as a written invitation to communicate about such a tendency. It asks for the patient’s judgment, not the professional’s. There is less danger of it being offensive or being perceived as threatening. By writing down their reflections at home patients were considered to reach more self-determined conclusions about their
**Figure 6.2.**
Essentials of Guided Self-Determination (GSD) designed to guide patients and professionals through autonomy-supportive problem solving drawing on worksheets filled in by patients before and between about 8 sessions. Worksheets marked* are obligatory, Δ are in a start pack received about 1 week before the first session. Central worksheets marked° are filled in and afterwards put in a co-operation folder in the patient’s record.

<table>
<thead>
<tr>
<th><strong>Five stage process</strong></th>
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<td>Self-understanding</td>
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<td>Action</td>
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<td>Feed-back from action</td>
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<th><strong>Advanced professional communication skills</strong></th>
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<td>Mirroring</td>
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<td>Active listening</td>
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<td>Values clarification</td>
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<td>I-you-sorted communication</td>
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<tr>
<th><strong>Worksheets (WS)</strong></th>
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<td><strong>Relationship</strong></td>
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<td>WS 1a. Invitation to work together*Δ</td>
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<tr>
<td>WS 1b. Progression form*○</td>
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<tr>
<td><strong>Your life with diabetes</strong></td>
</tr>
<tr>
<td>WS 2a. Important events and periods in your life* Δ°</td>
</tr>
<tr>
<td>WS 2b. What do you find difficult at present living with diabetes?* Δ</td>
</tr>
<tr>
<td>WS 2c. Unfinished sentences – your needs, values, habits and opportunities* Δ</td>
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<tr>
<td>WS 2d. A picture, metaphor or expression for your life with diabetes*</td>
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<td>WS 2e. Room for diabetes in your life*</td>
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<td><strong>Between ideal and reality</strong></td>
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<tr>
<td>WS 3a. Your experiences with recommended ways of living* Δ</td>
</tr>
<tr>
<td>WS 3b. Your plans for changing your way of life* Δ</td>
</tr>
<tr>
<td>WS 3c. Own experiences with different types of treatment* Δ</td>
</tr>
<tr>
<td>WS 3d. Your ideal goal for your blood glucose*</td>
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<td>WS 3e. Blood glucoses, as you know them from experience*</td>
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<td>WS 3f. Advantages and disadvantages of high and low blood sugar*</td>
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<td>WS 3g. Blood sugar checks and your reasons for checking*</td>
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<td><strong>Change work</strong></td>
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<td>WS 4a. Current problem solving*</td>
</tr>
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<td>WS 4b. Dynamic judgment of current and future problem solving*○</td>
</tr>
<tr>
<td>WS 4c. ‘Pros and cons’*</td>
</tr>
<tr>
<td>WS 4d. ‘More of’</td>
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<tr>
<td>WS 4e. ‘Less of’</td>
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<tr>
<td>WS 4f. Mapping behaviour</td>
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</table>
own response. Communication about this response had thus already started before patient and professional met at the first conversation. The unfinished statement and the patients’ words on paper would be the starting point of the conversation.

Changing the interaction between patients and professionals from one based on compliance to one based on person-specific autonomy support implied a considerable change in both patient and professional attitudes. This was quite an ambitious change, especially when it had to take place in spite of the limited time available in busy clinical practice and in the face of patients’ pent up resistance to professionals. This was another reason for using worksheets, the idea for which was borrowed from Swedish general practice research. Sixteen of the twenty worksheets were developed on the basis of the research carried out. Three (WS 4c,d,e) were borrowed directly from Arborelius 1:2. One (WS 4f) was borrowed from a life skills study 3.

Patient ‘homework’ has been used in life skills training for different groups of people and in cognitive therapy for patients with psychiatric disorders such as depression 4:5. Worksheets provide a chance for self-reflection and for considering issues in peace and quiet in order to make more self-determined decisions.

At the same time they save time for both parties as conversations come more easily to the heart of the matter when patients are well prepared. The drawings used replace the need for many words 6. Educationally the approach corresponds to the idea of using knowledge maps as proposed by Dansereau et al. as a way of enhancing teaching 7 and increasing the appraisal dimension of learning in accordance with recent brain research 8. The sheets furthermore offer an open framework with room to include each individual’s unique considerations 9.

6.2.2. Assuring applicability of GSD in clinical practice

Although GSD is supposed to have interdisciplinary implications, it was only implemented monodisciplinarily in the current study. Nurses were included as they belonged to my own profession and nursing ideology was considered to be close to the ideology inherent to GSD. As a certain foundation in diabetes care was needed, only nurses with at least one year’s experience in traditional diabetes care were asked to participate. The other professionals, doctors, dieticians and nurses in the team were informed about the intervention and encouraged but not obliged to look at GSD worksheets, which were kept in a ‘co-operation folder’ in the patients’ records. GSD was developed on the basis of an interpretation of the inadequacy of current problem solving between patients with poor glycaemic control and diabetes professionals, mainly nurses.
From earlier intervention studies I knew that the nurses involved in participatory research would ask questions which were extremely important in developing meaningful and applicable theories and methods for practice. I therefore planned a two-stage development for GSD: The first stage was developed according to the difficulties revealed in the grounded theory studies while the second stage was an evolved version, which was improved by the questions asked by the nurses who had applied parts of the method in busy clinical practice. I only had confidence in the applicability of the latter version. An outline of GSD was thus developed and was further refined through participatory research in dialogue with diabetes nurses and patients in busy clinical practice at two specialised diabetes units.

For 2 years (1998-2000), nurses participated in the development and implementation of GSD along with developing skills in using GSD. Seven sessions conveyed the theoretical idea of GSD, partly through findings from the grounded theory studies and partly through formal theory10-13 (Figure 6.3)(Appendix C). Subsequently twelve nurses and 25 patients with Type 1 and 2 diabetes volunteered to use parts of GSD as a supplement to ordinary admission procedures or outpatient care. Nurses received individual and group supervision as needed. Finally nurses trained in the communication skills judged to be necessary for GSD. GSD proved acceptable and applicable for patients and diabetes nurses in difficult diabetes care. An overview of the findings behind and purposes of each worksheet was developed and accepted by nurses. As the interaction between professionals and people with Type 1 diabetes and persistent poor glycaemic had been most difficult, GSD was finally adjusted to this patient group.

Figure 6.3. Content of GSD-training of professionals.

- 7 sessions conveying the theoretical idea of GSD
- Practising use of GSD worksheets under supervision from researcher
- 3 sessions comprising communication training
- Training in communication skills for typical difficult situations identified in the grounded theory study

I-you-sorted relationships were established between patients and professionals as the framework for GSD instead of the currently used combination of I-you distant provider dominance compensated by I-you blurred sympathy (Chapter 4). This was accomplished by inviting patients to
<table>
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<tr>
<th>Table 6.1. Findings in current care</th>
<th>Worksheets and footnotes</th>
<th>The aim of each worksheet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients showed up with reduced expectations at admission, having adapted to a purely disease-oriented scope and a passive patient role. Seldom had defined, conscious goals for hospital stay.</td>
<td><strong>Invitation to work together (1a)</strong> One-to-one version Group version</td>
<td>To expand patients’ expectations. Make them prepared to take an active role within the scope of their currently perceived difficulties in living with diabetes.</td>
</tr>
<tr>
<td>Unclear what decisions were made concerning issues to investigate and remedy during admission. Neither patients nor nurses were able to say what they had selected to work with or omit. Lack of clear decisions left the impression that everything could be worked with. Lack of selection caused lack of investigation. At discharge no agreements were made for future. Hospital stay appeared to be an isolated and closed period rather than part of a continuity. Patients experienced that the team in general did not know their situation well enough. For example, they perceived that nurses had gained knowledge which they did not pass on to the doctors. Patients viewed this negatively. Nurses experienced that doctors were seldom interested in learning what they knew about patients. When difficulties were presented in long and fairly unstructured narratives, doctors would lose interest after a short time. Patients frustrated over frequent staff changes.</td>
<td><strong>Progression form (1 b)</strong>&lt;sup&gt;1&lt;/sup&gt; <strong>Saved in the patient’s medical record</strong></td>
<td>A selection and sorting tool. Contains lists of problems perceived by patients and professionals, and a list of agreed problems to solve during hospital stay/course. Reveals and legitimises different points of view of patients and professionals. saves person specific knowledge for future care. Specifies goals agreed upon at discharge to be reached by next out-patient visit and the support needed from professionals and others. Informs members of the primary team, in order possibly to maintain continuity in the out-patient clinic. Provides the diabetes team with an overview of the issues chosen in order to mobilise diverse resources aiming at interdisciplinary problem solving. Problems posed in a short and precise form verified by patients and acknowledged by the nurses. Gives person-specific difficulties a structure that is easy to convey.</td>
</tr>
<tr>
<td>Problematic issues or events earlier in the patient’s life impeding current management of diabetes. Though nurses spent quite some time having patients talk about their life with diabetes, they often</td>
<td><strong>Important events and periods in your life with diabetes (2 a)</strong>&lt;sup&gt;2&lt;/sup&gt;</td>
<td>Patients’ stories are preserved in order to form a general view and promote identity. Makes patients aware of past, present and future. Hospital stay/course provides choices important</td>
</tr>
</tbody>
</table>

1 Fleiner and Sjøbakken, J. 23,24 introduced the term ‘I-you sorting’ during courses in communication and change.
2 From the many shades of life stories applied in health care, a life line version was adapted to diabetes 25,26.
<table>
<thead>
<tr>
<th>Missed important time-related information e.g. How long had the patient been poorly regulated? When was the onset? Had there actually been longer periods of good regulation? How was this possible? Though wishing to tell their story, patients were tired of repeating it several times to different professionals. Patient number A4 and A11.</th>
<th>In start pack Saved in the patient’s medical record</th>
<th>for future. Facilitates recall of important events and periods in past connecting them with glucose control. Patients have a chance to become aware of connections between life and disease not discovered previously.</th>
</tr>
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<tbody>
<tr>
<td>Often nurses focused on general problems and doctors on disease oriented problems. Patients did not say what the real problem was for them. Sometimes a lot of time was spent talking about something actually irrelevant.</td>
<td>Present difficulties in living with your diabetes (2 b)</td>
<td>Draws patients’ attention to current difficult issues. Invites them to express issues in their own words.</td>
</tr>
<tr>
<td>Patients were frequently not aware of certain areas inhibiting their problem solving in daily life. These areas could be painful or embarrassing for them to talk about or even think of. Sometimes they constituted blind spots. Patients seldom expected professionals to find these areas relevant.</td>
<td>Unfinished sentences - needs, values, experiences and opportunities (2 c)</td>
<td>Facilitates consideration and communication of difficult areas, reassessing what is really difficult for the patient. Gives quick information about many issues.</td>
</tr>
<tr>
<td>Many patients spontaneously described their situation by means of metaphors, which often revealed an overall attitude to having to live with diabetes. Sometimes extremely negative or life restricting. Patient number A1, A10, A11.</td>
<td>A picture, a metaphor or expression for your life with diabetes (2 d)</td>
<td>Pictures, metaphors and set expressions can be regarded as a gift from deeper levels of the consciousness, which are generally difficult to reach but can reveal patients’ overall attitudes to diabetes to both themselves and professionals. When expressed through drawings or words, such attitudes can be the subject of communication. If negative or self restricting, the attitude can be challenged or modified on the professionals’ initiative.</td>
</tr>
<tr>
<td>Some patients were intensely concerned about their disease and this constituted a considerable part of their problem. Apparently professionals found this reaction too difficult to talk about and accordingly did not comment on it (patient A11). Likewise it seemed difficult for them to approach the opposite problem of patients tending to neglect their diabetes. Patient A11, B17.</td>
<td>Room for diabetes in your life (2 e)</td>
<td>Patients asked to judge how much room diabetes currently takes up in their life by shading the corresponding area of an oval shape and asked to do the same for their intentions about how much room to give diabetes in future. Patients able to distinguish between negative and positive ways that diabetes can take up room. Provides a chance to make self-determined decisions about changing the room for diabetes in the short or long term, specifying the changes required. May help patients express their first acceptance of diabetes.</td>
</tr>
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</table>

3 Inspired by an open health concept developed by Wackerhausen
4 A method inspired by values clarification
5 Metaphors may reflect and maintain a positive or negative attitude to diabetes
As diabetes behaviour affects many different aspects of daily life and time was limited, professionals lacked a broad view of each patient’s lifestyle. Face-to-face communication was often of a general nature, and patients’ character and experiences were not extensively explored. Feelings such as bad conscience or frustration seemed to mean that the slightest trace of a moralising tone in professionals’ way of asking could mobilise resistance in patients. Changing lifestyle seemed to be treated as an event and not as a process. Consequently, traditional ways of supporting lifestyle change only met the needs of people who were ready to change and not those who had not yet decided to change or people who needed help to maintain newly implemented changes.

Professionals lacked a broad view of which of the recommended rules for life patients were not following. In addition, they did not know about patients’ readiness to change in specific areas. Time, energy and effort had till now been applied quite uncritically. Professionals were frustrated when their effort was wasted. Changes that had not been agreed could cause resistance to change in some people, and in others resulted in attempts at change that were doomed to failure because the decision was not self-determined.

Patients were angry and frustrated that they were not asked about their experiences and suggestions when they were not invited to do so. However, patients often had some good ideas, which they kept returning to and using energy on as they became annoyed when not listened to. Many patients were afraid of the side effects of different kinds of medicine and experiences. They also had some ideas, which they kept using energy on.

Patient number 1A, 8A, 11A.

Prochaska’s stages of change theory was used as a sort of screening tool to ascertain the need for and readiness to change separate areas of behaviour.

A power difference inevitably exists between patient and professional. According to Løgstrup’s power analysis, power is not to be avoided but is rather to be used appropriately. In the case of medicine, it is assumed that patients will not explicate their suggestions if they are not invited to do so.
Patients did not have ownership of general goals for HbA1c stated by professionals. Difficult to translate HbA1c into blood glucose values and vice versa. Many had neither set personal goals for blood glucose or HbA1c. Usually professionals did not know the patient’s goals. Many patients regarded blood sugars as belonging to themselves and HbA1c as belonging to the professionals. HbA1c has developed a nickname - the “tell-tale test” – maintaining its role as the professionals’ control tool and not as a tool for patients to use. Patients thus miss the HbA1c-value’s long-term significance for prediction.

Many patients did not test their blood sugar regularly and many did not test it after meals. They were therefore unaware of typical levels or variations.

Patients warned about the risk of late complications due to high blood sugar without having a clear picture of the amount of risk at different levels. They were also unaware of the amount of risk for serious events of low blood sugar depending on different glucose levels. They were thus motivated to achieve a lower blood sugar more by threats than by actual awareness of the specific advantages or disadvantages of different levels.

Following firm requests by nurses, patients appeared to measure blood sugar during hospital stays for controlled reasons. Stopped measuring shortly after discharge. Some said that they stayed away from their appointment at an outpatient clinic if they had not checked blood glucose as they were expected to do. Others said that they lied about their blood sugar and, for example, invented values or wrote down values measured months ago. Patients apparently tended to check blood glucose for the sake of professionals.

### Blood glucoses as you know them in reality (3e)

By writing down 8 values from a typical day or question marks for times where they did not know the value, patients got an insight into their own knowledge of blood-glucoses. Having 8 measures they were also able to calculate a mean value translating it into HbA1c by imagining that all days were like a typical one. Comparing this value with the previously stated ideal, they arrived at the difference between their current level and own ideal. Scale provides possibility to compare BG results and HbA1c.

### Advantages and disadvantages of high and low blood sugar (3f)

Results from a DCCT study linking deterioration of eye complications on the one hand and serious events of low blood sugar on the other. Risk, stated in events per 100 years at risk, is illustrated by imagining 20 patients living 5 years at risk at three different HbA1c levels (5.5, and 7.0 and 10.5). Patients asked to consider the advantages and disadvantages drawing on their personal experience and taking situations in their daily life into account. Patients asked to set goals for their HbA1c at four intervals during the coming year.

Blood sugar checks and the reasons for checking (3g)

Asking patients to assign a letter to each self-measured blood sugar result depending on the motivation for testing, enables them to distinguish between and be critically aware of their own reasons for measuring. Patients are recommended not to measure for professionals’ sake and rather to find their own reasons for measuring and developing curiosity about knowing how BG responds to certain behaviour or events. Scale provides possibility to convert mean BG results to HbA1c.

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8 According to Williams\(^{30}\) and Sheldon\(^{31}\) internal motivation and self-concordant goals for blood glucose levels will enhance glucose control.
Professionals knew very little about patients’ ways of solving problems.
Frequently a discrepancy appeared to exist between patients’ knowledge, goals and behaviour.

Professionals had till now only had a fragmented picture of fairly uncritically selected elements from a broad section of the patient’s life and lacked an overview of the dynamics connected with a problem mutually identified and agreed on as worth solving.

Professionals had till now not named the patient’s problems systematically, causing them at times to discuss two different problems without being aware of it.

Professionals were supposed to know the patients’ problem solving abilities regarding 1-3 issues. For each of these issues patients are guided through 4 pages and write their current 1) observations, 2) thoughts and feelings, 3) goals and 4) actions. Questions on these pages encourage patients to balance their own and others’ interests, and short and long-term interests.

Patients had at times a fixed view of the advantages or disadvantages of certain issues. They thus seemed unable to discover contrasts and the fact that their own opposing interests might actually obstruct decision-making.

Despite having decided to change, carrying through and maintaining change was difficult. Even admitting the starting point appeared to be embarrassing. Often the magnitude of the intended change made patients tend to give up beforehand.

Despite having decided to change, carrying through and maintaining change was difficult. Even admitting the starting point appeared to be embarrassing. Often the magnitude of the intended change made patients tend to give up beforehand.

Pros and cons (4 c) Helps patients specify advantages and disadvantages connected with maintaining or changing a specific behaviour. Finding their own reasons to change or maintain behaviour increases autonomous motivation.

More of (4 d) Is applied when patients have decided to implement a change requiring a measurable increase. Helps the patient specify and admit the starting point and take into consideration the facilitating or obstructing factors ahead. Helps them divide up the task by setting manageable goals without losing sight of the long term goal.

Less of (4 e) Is applied when patients have decided to implement a change requiring a measurable decrease. Helps the patient specify and admit the starting point and take into consideration the facilitating or obstructing factors ahead. Helps them divide up the task by setting manageable goals without losing sight of the long term goal.

Worksheet 3g was changed letting patients consider critically their own motivation to check blood sugars in order to facilitate the idea of autonomy support implementation.

Bos’s model of dynamic judgment building is regarded as being the core of Guided Self-Determination as it can advance the dynamics and coherence of assessment. The content of 4a’s four sheets is summarised on 4b’s one sheet.

Worksheets 4c-e were developed by Arborelius
Sometimes difficult feelings provoked a fixed pattern in patients’
behaviour. These were linked and were difficult to recognise and
therefore to change.

| Mapping behaviour (4 f) | By recognising a difficult feeling that provoked such a pattern
|------------------------| and tracing step by step the behaviour provoked by this
|                        | feeling, patients were able to see whether their behaviour
|                        | affected their situation negatively. Furthermore, they were
|                        | able to see steps for alternative behaviour. |

---

12 Developed by Newbern et al. and tested in life skills training of sub-groups
work together with professionals and by explicitly acknowledging the importance of both patients’ and professionals’ knowledge and experience as well as legitimising difficult feelings and different points of view in the relationship (WS 1a). GSD was used in a five-stage process initiated by establishing I-you-sorted mutuality and then proceeding through four phases recommended by life skills training\textsuperscript{15}: a) self-exploration, b) self-understanding, c) action and d) feed-back from action (Figure 6.3).

6.3. Evaluation of the clinical significance of GSD in one-to-one settings

When GSD had developed sufficient stability and nurses were judged to be satisfactorily skilled to apply GSD in a one-to-one setting, a qualitative intervention study was conducted. Patients were asked by phone or directly during visits to an out-patient clinic if they would like to participate. Having agreed to participate, one week before the first conversation patients received a start pack containing seven worksheets, which they were asked to fill in (WS 1a, 2a-c, 3a-c, Figure 6.2 and Appendix D). Other worksheets were given to each patient according to the needs that it was perceived should be addressed between conversations. About ten conversations between nurse and patient were scheduled according to the patient’s individual preferences.

6.3.1. Sample

Careful consideration was given to sampling in order to judge the clinical significance of GSD under conditions for problem solving that were similar, or at least equally as difficult as, the conditions under which traditional methods were studied in the grounded theory study (Chapters 3-5). All of the patients included therefore had a long history of poor regulation and all had Type 1 diabetes, as the most complex difficulties in the grounded theory study appeared between Type-1 diabetes patients and professionals. One patient refused to participate and one was prevented because of personal reasons. The remaining eleven patients asked to participate agreed to do so (Table 6.2).

In accordance with the principles of theoretical sampling we intended to include patient-nurse dyads with barriers similar to those in the grounded theory study. Hypothesised patient despondency and professional reluctance were the main reasons for including three of the patients (B3, B4 and B7) while a hypothesised resistance to professionals and to the disease were the main reasons for including five other patients (B1, B2, B5, B6 and B10). The appearance of a noticeable element of I-you-blurred sympathy was the reason for including one patient (B8).
Finally, the possibility of assessing the importance of worksheets compared to the importance of professionals’ oral communication skills was the reason for including two further patients (B9 and B11).

Table 6.2: Characteristics of patients with Type 1 diabetes and nurses having applied GSD in individual training

<table>
<thead>
<tr>
<th>Dyad number</th>
<th>Sex F/M</th>
<th>Age years</th>
<th>Completed (C)</th>
<th>Partly (P)</th>
<th>Illness duration years</th>
<th>Late Complications</th>
<th>HbA1c at admission</th>
<th>Nurse seniority/experience in diabetes care</th>
<th>Conversation with colleague</th>
</tr>
</thead>
<tbody>
<tr>
<td>B-1</td>
<td>F</td>
<td>25</td>
<td>C</td>
<td></td>
<td>21</td>
<td>Yes</td>
<td>9.4</td>
<td>12/10</td>
<td>Dietician</td>
</tr>
<tr>
<td>B-2</td>
<td>F</td>
<td>45</td>
<td>Paused/Stopped*</td>
<td>14</td>
<td>Yes</td>
<td>10.4</td>
<td>2/2</td>
<td>Moved</td>
<td>Nurse</td>
</tr>
<tr>
<td>B-3</td>
<td>M</td>
<td>34</td>
<td>Pilot°</td>
<td>33</td>
<td>Yes</td>
<td>9.0</td>
<td>20/19</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>B-4</td>
<td>M</td>
<td>23</td>
<td>Paused/Stopped**</td>
<td>7½</td>
<td>Yes</td>
<td>13.7</td>
<td>2/2</td>
<td>Moved</td>
<td>Nurse</td>
</tr>
<tr>
<td>B-5</td>
<td>M</td>
<td>36</td>
<td>Pilot°</td>
<td>25?</td>
<td>9.0</td>
<td>15/10</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>B-6</td>
<td>F</td>
<td>25</td>
<td>C</td>
<td>15</td>
<td>9.1</td>
<td>15/10</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>B-7</td>
<td>F</td>
<td>20</td>
<td>C</td>
<td>10</td>
<td>Yes</td>
<td>13.1</td>
<td>17/23</td>
<td>Dietician</td>
<td></td>
</tr>
<tr>
<td>B-8</td>
<td>F</td>
<td>24</td>
<td>C</td>
<td>22</td>
<td>7.7</td>
<td>5/5</td>
<td>-</td>
<td>Nurse</td>
<td></td>
</tr>
<tr>
<td>B-9</td>
<td>F</td>
<td>23</td>
<td>C</td>
<td>8</td>
<td>8.5</td>
<td>15/10</td>
<td>-</td>
<td>Not taped</td>
<td></td>
</tr>
<tr>
<td>B-10</td>
<td>M</td>
<td>34</td>
<td>C</td>
<td>29</td>
<td>Yes</td>
<td>9.0</td>
<td>12/10</td>
<td>Not taped</td>
<td></td>
</tr>
<tr>
<td>B-11</td>
<td>F</td>
<td>28</td>
<td>C</td>
<td>20</td>
<td>9.7</td>
<td>20/19</td>
<td>-</td>
<td>Doctor</td>
<td></td>
</tr>
</tbody>
</table>

* Paused when nurse moved, would have started again with another nurse, but ceased because of time consuming treatment of skin complications.

** Stopped after nurse moved. Would have continued with another nurse but was prevented by travel activity

°Classified as pilot patients because GSD principles were not followed. Caused worksheet 3 g to be changed.

Patients were selected on the basis of information partly provided from the patients’ medical records and partly from the professionals’ experience. Further investigation during data collection verified or modified this first impression and led to the final selection of the sample included in this study. The health care providers trained in using GSD were all nurses with at least one year of experience in specialized diabetes care. Although all patients had about eight conversations, the length of their courses varied from 2 to almost 12 months because special consideration was given to individual preferences.

6.3.2. Data sources

Two conversations between the patient and the nurse were taped from each nurse-patient dyad, one at the beginning and one at the end of the course, to document what was discussed, planned, accomplished and evaluated by them. In addition, each nurse was asked to tape a discussion with a doctor, dietician or another nurse from the team, which she considered to be important in appraising
the patient’s situation. These conversations revealed observations, feelings, concerns and ideas that were exchanged internally in the diabetes team when patients were not present. In each case, all three conversations were listened to before semi-structured interviews were conducted, first with the patients after discharge and then with the nurse, revealing the experiences, considerations and feelings of both parties with regard to the interaction. Finally, an interview with the patient half a year later revealed how they assessed the outcome of the admission, taking into consideration the change accomplished or not accomplished in daily life with the illness. Worksheets filled in by the patient and nurse, were saved in order to evaluate the GSD process and the value of the person-specific knowledge provided through the worksheets.

6.3.3. Analysis

The taped interviews and conversations were saved and processed as sound files supported by the Qualitative Media Analyser (a computer program providing simultaneous access to the original auditory details of the data and connected transcriptions and notes during coding \textsuperscript{16}). The analysis comprised both inductive and deductive analysis applying the categories and theories developed in the grounded theory study.

The deductive analysis detailed the changes caused by GSD in the theoretical structures of keeping life and disease apart, relational potential for change and person-specific reflection. This analysis showed that GSD intervention caused the intended changes, which were also the changes expected according to the grounded theories. In addition, these changes were a reason for continuing the inductive analysis in order to further the theoretical ideas and connections. This revealed that co-created knowledge of person-specific difficulties, which had earlier been identified as a core category (Chapter 3), had an important releasing property. Consequently renamed releasing knowledge, this core category appeared to move through four stages: Releasing knowledge 1) in the mind, 2) in a supportive relationship, 3) in a team and 4) in daily life. Releasing knowledge was revealed to have the ability to remedy the problem of keeping life and disease apart by starting a process of bridging life and disease.

The analysis developed resemblances ‘to abduction’\textsuperscript{17}, which comprises both inductive and deductive analysis and has been defined as a humanistic spiral of inductive and deductive processes. The analysis of the change caused by GSD profited from patients’ increased ability to reflect on their own situation before and after the GSD intervention, which in turn provided an augmented picture of the difficulties that could be remedied by GSD.
6.3.4. Validity
The validity of conducting a qualitative evaluation of a method one has oneself created can rightfully be questioned. In my endeavour to ensure the necessary distance and keep a clear focus in this evaluation, I was supported by again using the same sources of and procedures for data collection mentioned earlier, in accordance with the same critical issues stated prior to the grounded theory study (Chapter 2, p 22).

The danger of a type III error\(^\text{18}\) (concluding that an intervention is not effective when it has not been implemented as designed) was quite evident, as the intervention involved difficult and changeable professional attitudes and habits. The qualitative evaluation prevented a type III error by listening through the conversations between patients and nurses right after they had been taped at the start of the course. In two of the first dyads (B3 and 5), the nurses’ behaviour counteracted GSD ideas that patients should develop autonomous motivation for self-monitoring blood glucoses. These two dyads were classified as pilot dyads and worksheet 3g was subsequently changed in order to secure autonomy support when encouraging patients to self-monitor blood glucoses. The nurses were informed about the change and afterwards had no difficulties in providing autonomy support on this subject.

If the intended goals were accomplished by using GSD it would confirm the validity of the grounded theory findings (Chapters 3-5), GSD’s consistency with these findings and its ability to improve the effectiveness of relational problem solving.

6.3.5. Ethics
Informed consent was obtained from all participants, who were assured that their statements would be handled anonymously and confidentially. The protocol was prepared in accordance with the Helsinki declaration and approved by the ethics committee of Aarhus County.

6.4. Findings
The obvious difference of the new approach appeared to surprise the patients as expressed at the start by the patient in dyad 6: "That was absolutely not what I had been expecting when I came home and sat down with the questions. I thought to myself, "Christ, is that the angle they’re taking on this?"
6.4.1. Changes in relationships

I-you sorted mutuality (Chapter 4) was partly facilitated by the fact that the worksheets gave the first word to the patients and were in addition arranged so that both parties’ perceptions of difficulties were at first listed separately on the progression form (WS 1b). Furthermore, professionals’ improved communication skills helped them to communicate in an I-you-sorted way as was seen in dyad B6 in the nurse’s response to the impression the patient gave of her current relationship with professionals.

Patient. Then it slips away. It doesn’t help anything anyway. It’s still on 9 something or other. Then the carrot disappears, what could keep you trying, you know: When I deliver it next time: ‘Noo, they’ll be really happy if I’ve got it down to this or that’.

Nurse: Can you hear what you are saying? “Then they will be happy”?

Patient: Yes, I am completely clear about the way I phrased it.

I would really like to get rid of this idea that someone else is responsible for me, that you are the ones who are responsible for me. That’s the easiest way to put it. And it’s your fault that I don’t come. It’s your fault that I don’t have good blood sugar. It’s easy.

Yes, it’s not so conscious. It’s not like I actually think, ‘It’s their fault,’ but that’s the way it works, I think.

Changes in the relationship were noticed by patients, who perceived that their ability to talk about difficult matters was markedly enhanced, as noted by the patient in dyad 1B:

Patient: But I think the important thing was that you had personal contact, that I was allowed to say what I felt. And then that there was somewhere in the papers which was about how we, the nurse and I, should behave towards each other and that it was alright to use big words and...because then you’re in the same shoes...

Patients said that they were tired after each session, as they had talked about difficult issues they had never discussed with anybody before.

6.4.2. Changes in accordance with the ‘person-specific reflection model

The most striking change was seen in the ability to talk about difficulties in living with diabetes. In the grounded theory study without GSD, communication had circled around these difficulties, seldom reaching zone 5 (as described in Chapter 5). This pattern changed completely when
patients’ words from the worksheets they had filled in were used as the starting point in communication.

   How this was done appears from the communication at the start of the course between the nurse and the patient in dyad 6. Talking about the patient’s answers to unfinished sentences in WS 2c, the nurse needed only to read out the patient’s answers and this was sufficient encouragement for the patient to go into detail about the answer.

Nurse:   And you, “Stand alone with it”. What do you mean by that?

Patient: That’s because I shut everyone else out, because it’s just embarrassing you know that you can’t sort it out yourself. Because it’s just so easy. It is for everyone else. For them it’s incredibly easy. “Yes but you just have to…”

Patient: I would actually prefer that nobody else tried to get involved. If someone tries to get involved, I get angry because they don’t know what it’s like, do they?

The unfinished sentences in WS 2c thus functioned as written invitations to communicate in zone 5 about what exactly was difficult for the patient. Written reflections prompted by these invitations made patients identify and express difficult matters and thus prepared them for talking with the nurse. The effectiveness of this process as perceived by patients who had never been honest about those difficulties before, was explained by the patients in dyad 1 and 6:

   And little by little she put her finger on the things that really were wrong because I had never ever told anyone before that I had forgotten to take my insulin in the evening ....
   (patient in dyad B1)

   You know, it certainly got more intense because we were both ready that those were exactly the things we had to talk about, so it didn’t just roll along and I could say, ‘Well, yes it’s going really well.’ I couldn’t just say that, could I? Because I was the one who had sat back home and discovered that it wasn’t like that. (patient in dyad B6)

Even when patients had not written anything, the nurses just had to read the first part of the sentence, for instance: “Things that can give trouble at home...” and say, “You haven’t written anything there”. Patients might then answer, “No, because ...” and talk about the difficulties they perceived.
Without GSD it was very time consuming to identify these difficult matters and patients and professionals seldom succeeded. This pattern changed totally with GSD, as is seen from comments made by the patient in dyad B6.

Anyway, one of the first papers really got to the heart of the problem.

It was quick. Yes, it was really easy. It was dead quick. Yes, you know, it was right almost from the first time - we started on the papers and had to find out what the key points should be. And they were the same things we kept on coming back to. You know - they didn’t change as we went along. It was actually me who decided what they were but I also think it was also because those were what the problems were. There wasn’t so much to discuss.

Mutual reflection at level III and independent patient reflection at level IV were also reached easily (Chapter 5) and experienced by both nurses and patients, as appears from the following statements:

I just needed somebody who could, you know, support me in the things I found out, dug up from the depths... I think some things came out that I actually hadn’t been clear about myself... Yes, but God! I’ve never ever thought of it that way. I think she got a great insight into how I think and how, you know, it works inside my head.

It was just so intense, you know. It just went along. It was a bit strange to think, “God what have I been talking about for so long, and I’m dry in the throat and yes... the time has just gone.”

(Patient in dyad B6.)

That professionals’ view of patients might change completely through this knowledge was experienced several times.

A lot of things came out about her that I just had no idea about.
I thought I knew her but it turned out that I didn’t know her at all in that way. In one of the first conversations something came out where I thought, ‘Ah, now I understand better.’ Some things also dawned on me.

(Nurse dyad B9)

As is clear from the quotes above, both patients and professionals were aware of the new insights they achieved through these discussions.

6.4.3. Changes in ‘Keeping life and disease apart’

Patterns connected with the core category of ‘Keeping life and disease apart’, which was revealed in the grounded theory study (Chapter 3), began to change and this implied that both life versus
disease conflicts within patients and within professionals as well as between the two parties were starting to be resolved. Part of the change was increased awareness of former tendencies, as expressed by the patient in dyad 6 after working with WS 2d.

*I think I have treated them like two completely separate things. Diabetes has actually been nothing to do with me except that it gave me a bad conscience but it actually didn’t have very much to do with me.*

These changes appeared to be characterised by openness and the beginnings of acceptance, as expressed by the patient in dyad B1 in the interview at the end of the course

*Everything was turned upside down. She really poked some holes in some things - which I had hidden away. She’s maybe made me more open – to accept that I have diabetes and have to live with it. It has become a bigger part of my life, made me a bit more careful some places.*

Resistance to self-measurement of BG began to disappear as part of resolving the life-versus disease conflict. This process appeared to start with openness about checking BG, which could be regarded as a kind of communication, as explained by the patient in dyad B6 in the interview eight weeks after the start of the course:

*When we meet up for my dinner club with my friends, I have my blood sugar device with me and they certainly don’t get to see the result but they see that I DO it. And I’ve never done that before. It’s a big step in communication for me. And that was actually what I wanted to achieve - not having to sneak out with my bag. Taking care of it out in the kitchen or in a corner somewhere or something. I like that.*

Further development showed that diabetes became a natural and visible part of daily life with increased frequency of self-determined BG checks. This change was described half a year later by patient B6 in an interview:

*So I measure at least 4 blood sugars every single day and I can’t LIVE without it because then I have no idea of where I’m at. So even though I often have a good idea of the result before I do it, I just can’t accept taking insulin without taking the blood sugar test first. So it’s a real set routine. It’s very demanding of course because you’re aware of it, you know. It’s certainly a positive awareness.*

*When I go home on holiday and things like that my little bag with the blood sugar device and insulin sits out in the kitchen. It’s, you know, it’s the place where everyone*
meets and so every single time (I take a test) I go through there so they’re in no doubt that I am very aware of it.

In the past I’m pretty sure that bag lay hidden at the bottom of everything else (laughs) in the bedroom somewhere or other. But now I really don’t want it sitting in there because that’s not where I have to be, is it? It has to be where I AM, so it has to be in the shared space, doesn’t it? Because of course it has to be used all the time. That’s something they (the parents) have never experienced before - seeing me take a blood sugar test every single time we’re going to eat and every single time we’re going to do something or other. I just have to...

Resistance to self-measurement of BG appeared to have had serious consequences. Patients thus talked about constantly having a bad conscience because of not measuring BG. In addition, not measuring BG as they had promised to do resulted in patients frequently staying away from appointments at the out-patient clinic or making up BG results, as described by the patients in the following quotes:

Also because if you asked me to measure my blood sugar in the past, then I just wrote some numbers down in the book. It was much easier than sticking a needle in yourself three times a day or however often it was. So you wrote some numbers down that were towards the high end of the scale but not too high.

(Patient in B1)

I think those consultations with the doctors - they go in and say, “It certainly doesn’t look good. You absolutely must take more blood sugars and then come again and we’ll see”. I’ve done that for years without it doing anything.

That quarter hour with the doctor. You feel so small, see, and sit there and cling to the chair, you know? And have such a bad conscience that you get tears in your eyes and you don’t manage to say that really I’m doing what I can. You say, “Ah yes. It just isn’t good enough, I really have to pull myself together”. Then you go home and you can’t do it anyway.

Uh, and then suddenly there are only three days (until the next out-patient appointment). How am I going to manage to take a month’s worth of blood sugars in three days, you know? So, you see – it’s easiest to cancel the whole thing. Or I’ve also turned up without any results, see, and then I might just as well have cancelled. Because of course no doctor can say anything when there’s no background information.

(Patient in B6)
Thus patients and professionals did not meet or were involved in problem solving on the basis of non-existent or false information about the patient’s glucose control. According to patients, personal aspects had not been taken into account before:

_They don’t take account of the personal side. All the things that meant it was difficult to do the blood sugar tests, they haven’t come out. But they did here because this time we had some worksheets where we could just put it all in so it came across very clear._

The _life versus disease conflict between_ patients and professionals also appeared to be resolved, as explained by the patient in dyad 1 in the interview at end of the course.

_I think that I myself have changed my attitude to the hospital service. That suspicion that they are here to make life difficult for you. I think it has become clear to me that they are here to help._

The nurse in dyad 9 had known the patient for several years. She had suggested the patient for the study, having experienced that no progress was being made and perceiving problem solving as being deadlocked. In the interview after the course, the nurse said that right from the first conversation she noticed that gaining a new understanding of the patient made her reluctance to be involved with the patient disappear.

_Yes, she seemed different. Before she seemed to me to be a sloppy girl, you know. Now I can better understand, there are so many difficulties she has to take into account. She had some things to fight with and so she had to learn to tackle those things before she could deal with her diabetes._

Another sign of the resolution of this conflict was the fact that the content of patient-provider communication became consistent with the content of interviews and conversations with colleagues. Professionals did not press patients to make changes and patient resistance to professionals disappeared. Conflicts in daily life became a frequent subject of communication, revealing that difficulties in communicating with other people about their diabetes, be it family members, colleagues or friends, were a sign of life skills that these patients needed to develop.

### 6.4.4. Releasing knowledge - furthering grounded theories

In the grounded theory study without GSD, examples of situational reflection at level III and IV, with the accompanying positive consequence of co-creating person-specific knowledge of lived difficulties with diabetes (Chapter 5), were seldom seen.
This pattern changed completely when GSD was used in the intervention study. As patients and professionals now frequently experienced that person-specific knowledge was co-created, further study of the category was possible and revealed its releasing property. This discovery resulted in the core category of releasing knowledge, which appeared to move through four stages 1) releasing knowledge in the mind, 2) releasing knowledge in a supportive relationship, 3) releasing knowledge in a team and 4) releasing knowledge in daily life (Figure 6.4).

**Figure 6.4. Releasing knowledge and the potential for change released at four stages.**

<table>
<thead>
<tr>
<th>Releasing knowledge in daily life</th>
<th>Potential for change in relationships with family, friends and colleagues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Releasing knowledge in a team</td>
<td>Interdisciplinary potential for change</td>
</tr>
<tr>
<td>Releasing knowledge in a supportive relationship</td>
<td>Relational potential for change</td>
</tr>
<tr>
<td>Releasing knowledge in the mind</td>
<td>Person specific potential for change</td>
</tr>
</tbody>
</table>

In the following, these stages of releasing knowledge will be detailed. Through these stages the potential for change that exists in different contexts was released and this in different ways supported the patient in a process of bridging life and disease (Figure 6.5).

**6.4.4.1. Releasing knowledge in the mind.**

Person-specific knowledge was already co-created when patients were sitting at home and answering the questions on GSD worksheets. The questions in the worksheets thus functioned as an invitation for professionals to communicate about difficult issues and reach reflection at level 4 (Chapter 5). Patients might thus be said to have gained an insight while writing their sentences or drawing their drawings on the worksheets. Insight gained in this way often surprised the patients, be it insight into the self, into relationships with other people or into connections between life and diabetes that they had not been aware of before. This happened for the patient in dyad 11 when
finishing one of the sentences from WS 2c which starts: “I get good support from…” As appears from a conversation with the nurse, reflecting on this sentence made her totally reappraise the support she had gained from her parents and discover that the support of her father and not of her mother, as she had believed, was valuable:

Nurse: How was it to do these worksheets?
Patient: It was hard. They were hard - they were - these questions. You don’t go round thinking about that stuff. Also the bit about my parents. I was completely speechless when I got to the result.

Also a new awareness of themselves might surprise the patients, as mentioned by the patient in dyad B6.

It really starts something off and then I think ”Oh, is this here me?” when I get to the point where I have to put words to it.

Becoming aware that they had given other people a false impression of being perfect at diabetes management was a frequent confession, as expressed by the patient in dyad B6.

My friends think that I’m really good at all of this because I’m good at giving that impression. I’m just in control of it. They just wouldn’t be able to imagine that I’m so sloppy about it.

I just create the impression that I’m in control of it because they mustn’t find out that it’s not going well, you know, because then the whole facade would crack, wouldn’t it?

The patients’ discoveries had thus reached the stage of releasing knowledge in the mind, which was necessary for releasing their own potential for change. Although this stage formed the foundation for the process of developing life skills with diabetes, reaching the higher stages of releasing knowledge seemed to be decisive for continuing the process of bridging life and disease. Insights and their outer expression on paper thus had to be communicated to other people.

6.4.4.2. Releasing knowledge in a supportive relationship

Patients stressed the importance of sharing their knowledge with a supportive person who showed interest over time in the developmental process based on releasing knowledge in a relationship.
Sharing their new insights appeared to be exhausting for patients who showed many feelings at this stage. They stressed, however, the importance of being honest, which for many seemed to be a new experience in relationships with professionals. “It is important to be honest,” was the answer from the patient in B1 when answering a question about how it had been to use the worksheets. “You are really the first person to know so much about me,” were the words used by the patient in dyad B6 to the nurse. She further explained this in an interview.

*She could certainly see from me that things weren’t going well for me. There was no reason to hide anything and there would certainly have been a strong tendency for me to do that before. I’ve seen myself do it so many times.*

Nurses were aware of the importance of patients reaching this stage, as the nurse in dyad 6 explained to a doctor.

*She’s told me all those bad things she hasn’t told anyone else, her boyfriend or her parents.*

Having reached the stage of releasing knowledge in a supportive relationship, an expanded potential for change appeared to be released. The professional knowledge and experience of the supportive person in the relationship would thus be included in a dual process of co-creating and making use of person specific knowledge. An important change from before GSD was that unverified impressions were now replaced with verified knowledge.

An important consequence of sharing this knowledge was that agreement was reached on the specific difficulties that should be solved. While neither patients nor nurses in phase 1 (Chapters 3-5) had been able to answer which problems they had agreed to focus on, both patients and nurses in phase 3 quickly and clearly described these problems in interviews. In addition, the difficulties perceived by both parties and which they had agreed to work on were listed in WS 1b, as appears from table 6.2.

For each of the issues agreed on (Table 6.2), patients filled in WS 4 which consisted of four pages. A summary of this was then transferred to WS 4b for dynamic judgment building between the patient and nurse, as illustrated by the example from dyad B1 (Appendix D).
<table>
<thead>
<tr>
<th>Dyads</th>
<th>Lists of problems stated by patients</th>
<th>Lists of problems stated by nurses</th>
<th>Lists of problems agreed on (WS 4a-b)</th>
</tr>
</thead>
</table>
| Dyad B-1 | 1. Eat too many unhealthy things  
2. Forget to take insulin in the evenings  
3. Rarely measure blood sugar  
4. Want to give the impression that I am doing better than I am | 1. Communication, to be honest with yourself and others  
2. Frequently forget to take insulin in the evening  
3. Rarely measure blood glucoses  
4. Want to give the impression that you are doing better than you are | 1. Want to give the impression that I am doing better than I am |
| Dyad B-2 | 1. Food (sweets, snacks)  
2. Acceptance of diabetes | 1. Acceptance of diabetes  
2. Snacks, weight  
3. Communication  
4. Tiredness | 1. Acceptance of diabetes |
| Dyad B-4 | 1. Self confidence  
2. Doing things for other’s sake  
3. Doing things for myself | 1. Self confidence  
2. Doing and saying things for other’s sake  
3. Deciding own limits | 1. Doing things for other’s sake |
| Dyad B-6 | 1. Do not take responsibility for the diabetes  
2. Food and insulin do not match  
3. Difficult to communicate about diabetes | 1. Difficult to communicate about diabetes being poorly regulated  
2. Afraid of low blood glucoses in job situations  
3. Taking too little insulin compared to blood glucoses, afraid of weight increase | 1. Food, blood glucoses, and insulin do not match |
| Dyad B-7 | 1. Lacking self confidence  
2. To control diabetes myself  
3. Frequent admissions (ketoacidosis) | 1. Lack confidence in own ability to control diabetes  
2. To communicate  
3. To express your needs  
4. Exercise/diet | 1. Lacking confidence in controlling own diabetes  
2. To communicate - express your needs  
3. Exercise/diet |
| Dyad B-8 | 1. Eat too much when blood sugar is low  
2. To adjust insulin/food  
3. Eat less fat | 1. Eat too much when blood sugar is low  
2. Anticipate changes, adjust insulin and food accordingly | 1. Eat too much when blood sugar is low  
2. Anticipate changes, adjust insulin and food accordingly |
| Dyad B-9 | 1. Eating habits/blood glucose/insulin don’t add up  
2. Not good enough to say “no” to extra jobs at work  
3. Do not exercise enough | 1. Weigh too much  
2. Eating too much when blood sugar is low/snacks too big – BG/insulin food  
3. Daily life/future | 1. Inappropriate eating habits/overeating results in high BG and weight increase  
2. Fitting exercise into daily life |
| Dyad B-10 | 1. Fluctuations of BG during exercise  
2. Muscle aches | 1. Measure too few blood glucoses  
2. Communication | 1. A challenge to measure BG when exercising |
| Dyad B-11 | 1. Food  
2. To get blood sugar measuring done  
3. Lacking self-confidence | 1. Eating too much fat and too many sweets, having a good time with the wrong things  
2. To express your needs  
3. Too few blood glucoses only done on good days | 1. Higher awareness of food  
2. To form a general view of BG regulation  
3. Express needs |
6.4.4.3. Releasing knowledge in the diabetes team.

Nurses seemed to be able to exchange person specific knowledge with other members of the diabetes team quite quickly and effectively. These exchanges appeared to be enhanced by referring to the worksheets and conversations with patients as well as to the list of problems agreed on in the progression form (WS 1b). A comprehensive exchange between the nurse in dyad 6 and a doctor, which consisted of a summary of the whole process, took 10 minutes and was appreciated by the doctor.

Doctor:  
It’s fine. It’s good. Because I mean she is a girl who wants to have control of it the whole time so it’s difficult to reach her in the out-patient clinic when you’re sitting there and concentrating. Because it’s easy to see that it’s not good, that her results are so high but either she doesn’t bring her results with her or the ones she does bring with her are fine, you know, so you can’t regulate.

As the intervention was not interdisciplinary, exchanging and retaining releasing knowledge in the diabetes team was only accomplished in part, by placing three key worksheets in a co-operation folder in the journal (WS 1B, 2a and 4b). Doctors and dieticians were briefed about the possible use of these worksheets, as repeated by the nurse in dyad 6 when finishing the conversation:

Nurse:  
And then we’ve worked with these one by one...and we’ve put them together in a file like this...so if you want to pull them out when you’re in a consultation with her, you can do it.

Person-specific knowledge communicated to members of the diabetes team was expected to be able to release a broader potential for change by mobilizing the diverse expertises of the interdisciplinary team. As it was not possible to fully develop this part of the intervention, we were only able to judge its possible consequences in relational problem solving to a limited extent. However, GSD appeared to make it easier to exchange person-specific knowledge and retain it in the diabetes team for future care.

6.4.4.4. Releasing knowledge in daily life

At this stage patients shared their new insights with family, friends and colleagues. Sometimes worksheets facilitated this exchange of knowledge, as explained by patient B1 in an interview.
I think it was one of the times I’d been in to talk with the nurse. We had to go to my grandmother’s grave afterwards with some flowers and then we drove home and my father asked how the talk had gone.

If it had been before then I would have closed in on myself. But instead I explained to them - very briefly of course - what sort of things we’d talked about and then I also said that they could see the questions and then I could explain them when we got home because, of course, I had all these (the worksheets) with me.

So we got home and had a cup of coffee and some bread I think it was and then I showed them the papers. And it didn’t matter that I was sitting there and talking about it. That time I didn’t get angry about telling them that there were some things that weren’t really alright.

Actually I think it was good to be able to tell them how things really are because I’ve often said, ‘Yes, you know, it’s going fine! It’s going well and I have to do this and this and this’ - and it’s actually the opposite of that.

The releasing effect of person-specific knowledge in daily life created, according to this patient, increased openness and humour.

My mother and father - I think they gave up some years ago. Then they went round - it was more a look - they never said anything.

It’s just like you can see it in my mother’s eyes when she thinks I’m lying. Then she looks at you in this strange way. And then I look away and walk off - that’s up to her - it’s my problem, not hers.

But she doesn’t do that anymore, that thing with looking at me so strangely when I take something.

A little while ago I took a piece of chocolate they had at home. Then she came rushing into the living room and asked, “Who’s eaten my chocolate?” you know, just for fun, and so I said, “I have”. “Ah, you can’t do that” - and it was just for fun - and we’ve never done anything like that before - just for fun.

Now, I mean, they’ve really calmed down I think. Just being able to sit down and talk to them about it. It makes it more open - the relationship we have.

This appearance of openness and humour instead of suspicion and worry in relationships between patients and family thus meant a positive change not only for the patient but for all family members. By becoming more open about their difficulties in living with diabetes, however, patients sometimes experienced that other people tried to interfere in their diabetes management, which might cause conflicts, which they had to develop the ability to solve.
Then my father started to ask some of these slightly personal questions about whether I remembered to take my medicine on time.

I was totally bloody furious inside because he’d started to pick at it. I was just about to jump up and slam the door and say, ‘I don’t want to talk about it anymore.’ The old me was just coming back and peeking out.

But then I took a breath and then the explanation came out calmly and quietly.

I explained to him - as close as I could get - that the things I have chosen and am going through in here, I mean to deal with and get better at, it wasn’t something I could learn in a day. It was something I had to practise remembering and using, you know, something with the blood sugar and that kind of stuff.

It was just like - my dad backed off completely. It was just so good, it really was. I can still remember it.

It’s just a shame that I didn’t learn this a while back. We’ve had fights about this so many times. It’s just been a bomb in our house.

Succeeding in developing such skills was really appreciated by the patients, as can be seen from the comments above made by the patient in dyad B1.

6.5. Process evaluation of GSD in one-to-one settings

6.5.1. A point of no return.

Some patients resisted getting started with the use of GSD partly because they had lost their confidence in new attempts after many years of failure and partly because they had to change their role from being compliant patients to raising awareness of their life as a whole. The patient in dyad B1 talked about this resistance.

I thought that I’d soon reach the point where I’d tried so many things that I couldn’t see how I ...that it would be able to change anything.

I actually didn’t really want to answer the questions but then it was those questions that got me thinking anyway.

So I got started with slightly mixed feelings. But I can remember that after I sat myself down I didn’t get to bed before 11.30 because I was sitting and thinking about those questions. I think I went ahead and answered it as if it didn’t really have anything to do with the diabetes, but instead with my dreams and my wishes and what I want in general.

And then I got to bed quite late anyway because I got caught up in it anyway.
This resistance only existed until a point of no return appeared to be passed as explained by the patient above. Often professionals could determine whether patients had passed the point of no return as this tended to be accompanied by obvious changes of attitude.

6.5.2. Schedule of the course adapted to participants’ daily life.
Knowing about patients’ daily life made it natural to consider individuals and schedule appointments in accordance with patient preferences.

My everyday life has been completely normal and it’s been possible to include it and I’ve kept going like I have up to now. I mean it hasn’t turned everything upside down and that’s why good results have come out of it.

6.5.3. Worksheets made it easier to get started and to ensure continuity.
As mentioned by the nurse in dyad 9, the worksheets were especially important for getting started and getting things moving.

The worksheets are a really good way of getting started with it. Then there comes a time when you drop them and talk without them. They just act as a lead in. What’s happened is that she herself has put it in words - that we’ve come up with some problem areas that have become clear to her. It was a mess before. (nurse in dyad B9)

Further advantages of worksheets were also seen in terms of keeping track of progress and ensuring continuity. This was especially obvious at one appointment with the patient in dyad B1. When she arrived at the clinic she had a high fever and pain because of an abscess that needed treatment. The nurse thought that she could forget everything about the worksheets they had agreed to look at. Nevertheless the patient had brought the worksheets and took them out in spite of her condition and all the other things that had to be done.

6.5.4. Easier to develop autonomous motivation by filling in worksheets at home
Perceiving that patients were bored in phase 1, I had imagined that they would fill in worksheets at the hospital. Some did, but others stressed the advantages of doing it at home for reasons similar to those explained by the patient in dyad B1:

Um, I think I took them (the worksheets) home and then I sat down and did them at home. In familiar surroundings you don’t feel that you have to write what the hospital
wants you to write and have some kind of suspicion that if you write this - there’s a doctor standing behind you and looking over your shoulder. So it’s easier to write it at home in familiar surroundings and you can relax better and dare more to write what you think - and not what they want to hear.

6.6. Discussion and conclusion concerning significance of GSD in one-to-one settings

If the goals behind using GSD were accomplished, it would confirm the validity of the grounded theory findings (Chapters 3-5) and the consistency of GSD with these findings.

Four goals of using GSD appeared to be accomplished. Firstly, the scope of problem solving easily included difficulties in developing life skills with diabetes through the patients’ reflections on worksheets. Secondly, patient-provider relationships were changed to an obvious extent, as both parties changed their roles and the old restricting patterns appeared to be resolved. Thirdly, zone 5 specific communication was promoted and easily maintained by patients and professionals through written invitations on worksheets. Lastly, nurses and patients more frequently co-created knowledge of person-specific difficulties through situational reflection at level III-IV. The frequent occurrence of co-created knowledge furthermore permitted the discovery of the four stages of releasing knowledge.

Figure 6.5. Conclusion on the theoretical structures in which GSD intervenes

Keeping life and disease apart

Releasing knowledge

In the mind
In a supportive relationship
In a team
In daily life

Bridging life and disease
Though empirically grounded, the overall goal of GSD was recognised as life skills with diabetes, comprising the development of balanced self-determinism in patients’ ways of solving problems and conflicts with diabetes.

GSD intervention in a one-to-one setting produced the changes expected according to the grounded theories developed in phase 1. Its clinical significance was, in addition, acknowledged by the people involved.

Some patients were expected to benefit more from GSD in a group setting than in a one-to-one setting and it was also expected that in this way more patients would be reached for less expenditure. It was therefore decided to adjust GSD to group-settings and test its effect in a randomised controlled trial (Chapter 7).

**6.7. GSD adjusted to group settings**

It was decided to use eight sessions for group training, which was less than the ten that had been the lowest number used in the individual courses. The shortest interval between individual sessions (one week) was also selected. The reason for these choices was an attempt to reduce the overall length of the group courses in order to avoid patients dropping out of the RCT.

The fact that participants might put pressure on each other and thus influence each other inappropriately meant that the invitation to work together was reformulated into a group version (WS 1a group version).

The worksheets for self-determined glucose control still needed some refinement in order to provide research based information of the advantages and disadvantages of high and low BG in an autonomy supportive way. This resulted in changes to WS 3 f before the start of group training, the development of educational material providing ‘translation’ of the results from the DCCT study and encouragement of patients to use HBA1c as their own landmark sample instead of regarding it as professionals’ *tell tale sample* (its nickname in Denmark) (Appendix D).

**6.7.1. Selection of content valid scales for testing effect of GSD**

Changes observed in the qualitative study guided the selection of scales for quantitative testing of the clinical and statistical significance of GSD in group settings. As no scales were available for testing the development of life skills with diabetes, we produced a questionnaire with scales providing proper content validity and internal validity. Four main domains seemed to be influenced by GSD: 1) Degree of the autonomy support that patients perceived from health care professionals,
2) Increase in patients’ autonomous motivation for self-management of diabetes, 3) Increase in patients’ perceived competence with diabetes and 4) Decrease in diabetes related problems perceived in living with diabetes.

In accordance with these findings, four scales were selected and translated for use in a randomised controlled study: 1) HCCQ, Health Care Climate Questionnaire, 2) TSRQ, Treatment Self Regulation Questionnaire, 3) PCD, Perceived competence with diabetes\textsuperscript{19} and 4) PAID, Problem Areas In Diabetes\textsuperscript{20-22} (Appendix D).

### Conclusion about the development, implementation and qualitative evaluation of GSD.

- GSD was developed as a new method for relational problem solving in clinical practice on the basis of grounded theory studies and participatory research (Chapters 3-5).
- Barriers connected with conflicting life-disease perspectives, inappropriate relationships and ineffective communication were all addressed by GSD.
- GSD draws on worksheets and advanced professional communication, Appendix D.
- GSD is adjusted to people with long standing Type 1 diabetes.
- GSD was tested in one-to-one settings by diabetes nurses and people with Type 1 diabetes and poor glycaemic control.
- By using GSD patients and professionals more frequently co-created knowledge of person-specific difficulties which proved to have a releasing effect in the mind, in a supportive relationship, in a team and in daily life.
- It is concluded that GSD has clinical significance in one-to-one settings.
Reference list


Ref Type: Personal Communication

Ref Type: Video Recording


Ref Type: Thesis/Dissertation


Chapter 7

Guided Self-Determination improves A1C and self-management of Type 1 diabetes in randomized controlled trial

Vibeke Zoffmann and Torsten Lauritzen.
Abstract

Objective - To report 1-year results of a newly developed method, Guided Self-Determination (GSD), applied in 16-hour group training (GSD-GT) for Type 1 diabetes patients with persistent poor glycaemic control.

Research design and methods - GSD was developed on the basis of qualitative research designed to help patients achieve self-determined glucose control. We randomized 18-49 year-old adults at a Danish university hospital to either GSD-GT in 2001 (intervention group) or to a group that received training 1 year later (control group). Inclusion criteria: mean A1C ≥ 8.0% for at least two years, disease onset ≤ 40 years and insulin treatment from onset. Thirty GSD-GT patients and 20 controls completed the study.

Results – GSD-GT patients did better than control patients in terms of self-management as measured by a) increase in perceived autonomy support from health professionals measured by Health Care Climate Questionnaire (p<0.01); b) higher frequency of self-monitored blood gluoses (p<0.001); c) increase in felt competence measured by Perceived Competence in Diabetes (p<0.01); d) fewer diabetes-related problems measured by Problem Areas In Diabetes (p<0.05); and e) improved glycaemic control over 1 year measured by A1C (p<0.01).

Conclusion – Patients with persistent poor glycaemic control experienced improved self-management of Type 1 diabetes and A1C one year after applying GSD in a group-training program. GSD is a worthy candidate for further development and investigation.

Keywords
Type 1 diabetes, autonomy support, motivation, problem solving, group training, glycaemic control.
**Introduction**

About 50% of people with Type 1 diabetes do not benefit from traditional interventions when trying to achieve a level of glycaemic control optimal for preventing disabling complications\(^1\)\(^-\)\(^4\) and this requires an innovation in diabetes management strategies for patients with persistent poor glycaemic control.

Though self-monitoring of blood glucose concentration has been associated with improved glycaemic control in patients with Type 1 diabetes, only 20% of the patients in the study redeemed prescriptions for enough reagent strips to test glucose daily\(^5\). 75% did not set personal goals for glucose and A1C levels\(^6\) and also tended to have difficulties in interpreting A1C levels accurately and remembering their last A1C value\(^4\). In accordance with self-determination theory, Williams et al. showed a correlation between patients’ perception of professional autonomy support and their possibility of lowering A1C\(^7\). Although the diabetes research related to autonomy support is convincing, qualitative research indicates that even patients in good glycaemic control report that professionals undervalue their experiential knowledge in decision-making\(^8\)\(^,\)\(^9\). A non-randomised study testing a cognitive behavioral training programme for adult Type 1 diabetes patients in persistent poor glycaemic control concluded that a more positive attitude to diabetes improved self-management behavior and hence glycaemic control\(^10\). A meta-analysis concluded that the greatest challenge in diabetes patient education lies in identifying creative ways of meeting patients’ individual needs under the economic constraints of the health care system and the time restrictions of diabetes educators\(^11\).

Grounded theory studies prior to the current study indicated that other-determined\(^12\) glucose control was a consequence of a widespread compliance expecting approach to problem solving. Barriers to developing on this approach appeared to comprise of the conflicting priorities of patients and health care professionals and patient resistance to self-measurement of blood glucose (SMBG). This study assumes that the methods currently used in relational problem solving such as diagnostic methods in nursing and medicine and traditional methods in diabetes education, are inconsistent with empowerment\(^13\) and need to be replaced with the apparatus needed to overcome the barriers identified. Guided Self-Determination (GSD) was developed in order to replace these methods and accomplish effective relational problem solving\(^14\)\(^,\)\(^15\). GSD has proved to have clinical significance in a one-to-one setting between nurses and Type 1 diabetes patients with poor glycaemic control and was adjusted to group-settings in order to meet the needs of the diabetes population within realistic expenditure limits.
**Aim**

This study was designed to test the effects of GSD applied in a 16-hour group-training programme (GSD-GT). More specifically, it tests whether GSD-GT is perceived to support autonomy better than traditional care and whether patients subsequently develop autonomous motivation for diabetes management, especially for self measuring blood glucoses (SMBG), achieve higher perceived competence with diabetes, fewer diabetes-related problems and lower A1C.

**Research design and methods**

GSD is designed to guide both patients with persistent poor glycaemic control and professionals through mutual problem solving drawing on a large number of semi-structured worksheets, some of which are obligatory, and relies on improved communication with health professionals (Figure 7.1). Patients are prompted to systematically explore and express their personal difficulties and experiences with diabetes through words and drawings. Reflections are recorded on worksheets designed to increase patients’ ability to express their views and prepare them for active participation in the care process. The time required for identifying person-specific difficulties in living with diabetes is thus reduced and the potential for change in patient-provider relationships is better exploited. Four worksheets are designed to prompt self-determined glucose-control (WS 3d-g). This approach is consistent with the philosophy of empowerment\(^{15}\) and proposes life skills\(^{16-17}\) as a stated goal for individual diabetes care. It includes worksheets for dynamic judgment building\(^{18}\) (WS 4a-b) and instruments based on trans-theoretical stages of change theory\(^{19}\) (WS 3a-b). The health care providers trained in using GSD were all nurses with at least 1 year of experience in specialised diabetes care. Different points of view between patients and professionals were regarded as holding a potential for change that could be exploited without the need to apply pressure.

**GSD group training**

Groups of about ten members met over eight weeks for 2-hour sessions. The researcher introduced the sessions, while GSD-trained nurses functioned as coaches in smaller groups, supporting and challenging patients in expanding their autonomous problem solving skills. Each patient and professional worked out two independent lists of issues that they each perceived to be difficult for the patient. Together they selected 1-3 issues from these lists, using names meaningful to the patient. Patients then examined their current strategies for approaching these issues and were challenged and supported by the nurse in order to develop alternative strategies.
Figure 7.1.

Essentials of guided self-determination (GSD) for people living with Type 1 diabetes in poor glycaemic control.
GSD is designed to guide patients and professionals through autonomy-supportive problem solving drawing on work-sheets filled in by patients before and between about 8 sessions. Work sheets marked * are obligatory, Δ are in a start pack received about 1 week before. Central work sheets marked○ are placed afterwards in a co-operation folder in the patient’s record.

**Five stage process**

- Establishing an I-you-sorted relationship
- Self-exploration
- Self-understanding
- Action
- Feed-back from action

**Advanced professional communication skills**

- Mirroring
- Active listening
- Values clarification
- I-you-sorted communication

**Work sheets (WS)**

**Relationship**

- WS 1a. Invitation to work together*
- WS 1b. Progression form○

**Your life with diabetes**

- WS 2a. Important events and periods in your life* Δ○
- WS 2b. What do you find difficult at present living with diabetes* Δ
- WS 2c. Unfinished sentences – your needs, values, habits and opportunities* Δ
- WS 2d. A picture, metaphor or expression for your life with diabetes*
- WS 2e. Room for diabetes in your life*

**Between ideal and reality**

- WS 3a. Your experiences with recommended ways of living* Δ
- WS 3b. Your plans for changing your way of life* Δ
- WS 3c. Own experiences with different types of treatment* Δ
- WS 3d. Your ideal goal for your blood glucose*
- WS 3e. Blood glucoses, as you know them from experience*
- WS 3f. Advantages and disadvantages of high and low blood sugar*
- WS 3g. Blood sugar checks and your reasons for checking*

**Change work**

- WS 4a. Current problem solving*
- WS 4b. Dynamic judgment of current and future problem solving○
- WS 4c. ‘Pros and cons’*
- WS 4d. ‘More of’
- WS 4e. ‘Less of’
- WS 4f. Mapping behaviour
A process of developing self-determined targets for A1C and glucose levels was initiated. Patients also indicated their readiness to maintain or change 15 diabetes self-management recommendations according to Prochaschas’ stages of change theory6;19. Their reasons for change were explored if they were considered not to be autonomously motivated.

Finally, patients were asked to set self-determined goals for future diabetes care. Three central worksheets (Figure 7.1) comprising person-specific knowledge and agreements on strategies for problem solving were saved in a folder in the patient’s medical record marked “co-operation papers” for follow-up at out-patient appointments. Appointments between nurse and patient during 1-year follow-up were arranged either individually or on a group basis according to patients’ preferences.

Participants
Participants were recruited among 18-49 year-old Type 1 diabetes patients who had attended one of two diabetes clinics at a Danish university hospital during the year 2000. Data from local hospital registers and laboratories were combined to identify diabetes patients with persistent poor control with a mean A1C ≥ 8.0% (ref. 5.1 – 6.2%) during 1999-2000 and at the time they were invited to participate in the summer of 2001. Patients whose diabetes had lasted for at least two years were considered eligible if they were ≥ 40 years of age at onset and had been treated with insulin from onset. All patients fulfilling the eligibility criteria received a questionnaire and an invitation by post. The patients who agreed to participate returned a written informed consent form together with the completed questionnaire.

Randomization
Randomization of volunteers took place at the two diabetes clinics. Written assignments were placed in sealed opaque envelopes numbered and stacked randomly. For practical reasons, three out of five patients were assigned to GSD-GT in the autumn of 2001 and two out of five to a control group receiving conventional out-patient treatment for one year while awaiting delayed group training. If two patients were closely acquainted they were assigned to the same group. All patients delivered a blood sample for an A1C test. Worksheets were not provided to the control patients as a qualitative pilot study had concluded that they were a decisive factor in achieving the pattern interruption required in the intervention. Blinding was not attempted as it was considered impossible due to the great differences between GSD-GT and traditional care.
Figure 7.2. Theoretical model. Measurements applied and changes expected 1 year after Guided Self-Determination was applied in 16-hour group training (GSD-GT) for adults with Type 1 diabetes in persistent poor glycaemic control.
Measurements

Self-administered questionnaires were answered at baseline and at 1-year follow-up. Danish versions of the following measures were used translated in accordance with recommended guidelines\textsuperscript{20}. All scales were Likert scales with satisfactory internal consistency of the English versions measured by Chronbach’s $\alpha$ (76-94). The Health Care Climate Questionnaire (HCCQ), Treatment Self-Regulation Questionnaire (TSRQ), and Perceived Competence in Diabetes Scale (PCD) were developed from self-determination theory\textsuperscript{21} and applied in the USA\textsuperscript{22}. Problem Areas In Diabetes (PAID) was developed in the USA and applied in a trans-cultural US-Dutch study\textsuperscript{23-24}. Patients also stated the frequency of their Self-Measured Blood Glucoses (SMBG) during the past week. The study used A1C values from hospital laboratories measured 2½ years before the course, at baseline and 3, 6, 9 and 12 months after group training.

Significant changes in the following measures would be seen as signs of improvement of life skills (Figure 7.2): An increase in HCCQ-scores, TSRQ-scores on autonomy or in relative autonomy index (formed by subtracting TSRQ-scores on control from TSRQ-scores on autonomy\textsuperscript{22}), PCD and frequency of SMBG per week; a decrease in TSRQ-scores on amotivation (lack of motivation), PAID-scores and A1C.

Statistical analysis

Statistical analysis was performed using SPSS 10.0 for Windows. The reliability and internal consistency of the Danish versions of the scales were tested using Chronbach’s $\alpha$ (Table 7.1). HCCQ, TSRQ and PAID data fell within normal distribution ranges and the significance of differences was tested using t-tests for independent groups and the t-test for paired data. Values are expressed as means and standard error (SE) or 95% confidence intervals (95% C.I.).

As data on PCD and the frequency of weekly SMBG were not distributed normally, significance was tested by using non-parametric tests, the Mann-Whitney test for independent groups and the Wilcoxon signed rank test for paired data. Values are expressed as median and interquartile range.

The A1C data were analyzed by means of a repeated measurement ANOVA allowing for both inter- and intra-individual random variation using Proc Mixed in SAS v 8.2. At the first step we tested the hypothesis that the difference between the 2 treatments (intervention/ control), with respect to development over time, depends on the interaction of the 3 terms: clinic, treatment and time. Given no significant interaction between the 3 terms, we assumed a general development
over time for each clinic and a general term for the difference between intervention and control for each time point following baseline. At the second step we tested whether the difference depended on time. If this proved not to be the case, we assumed there was a constant difference between intervention and control throughout the following period. At the third step we tested whether this constant difference was zero (no treatment effect). P-values < 0.05 were considered statistically significant.

**Sample size**
The inclusion of 50 patients (30 for GSD-GT and 20 as control) was shown to yield a power of 80% for detection of an absolute difference of 0.9% in A1C between groups and 0.6% within groups.

**Results**

**Participants**

1999-2000 A1C values averaged ≥ 8.0% for 397 (56%) of 713 Type 1 diabetes patients of whom 242 met the inclusion criteria and were invited to participate. The questionnaire and informed consent form were returned by 60% but 16 of these did not turn up at randomization leaving 61 patients for randomization to either GSD-GT (n = 36) or the control group (n = 25).

The study was completed by 30 intervention patients and 20 controls (Figure 7.3). The characteristics of the GSD-GT group and the control group did not differ significantly at baseline (Table 7.1). The 11 patients who dropped out also did not differ from the GSD-GT group or the control group (data not shown). The 30 GSD-GT patients who completed the study attended on average 7.0 (range 4-8) of 8 possible group-training sessions.

GSD-GT patients’ recollection of perceived autonomy support during group training was significantly higher (HCCQ = 30.7) than the autonomy support they perceived from health professionals at the out-patient visit before the study started (HCCQ = 26.9; p<0.01) and at the 1-year follow-up (HCCQ = 28.9; p< 0.05). HCCQ in the GSD-GT group exceeded that of the control group, which was 23.45 ± 1.57 at the 1-year follow-up (p< 0.01) (Table 7.1).
Figure 7.3. Flow of participants through the stages of guided self-determination programme, Aarhus University Hospital, Denmark 2001-2003.

Assessed for eligibility
713 Type 1 diabetes patients, 18-49 years old, had attended the clinics in the year 2000; 397 (56%) of whom had been living with an average HbA1c above 8.0% for two years according to the hospital laboratory.

Excluded (n = 336)
- Not meeting inclusion criteria (n = 155)
- Not responding to invitation (n = 97)
- Refusing to participate in group training (n = 68)
- Accepted participation in group training, but did not show up at randomisation (n = 16)

Randomized (n = 61)
balanced 3 to 2

Allocated to life skills group training 2001 (n = 36)
- Received intervention (n = 33)
- Did not receive intervention (n = 3)
  - One prevented due to job change, one due to divorce and one due to reluctance to participate in group setting

Allocated to control group and delayed training (n = 25)
- One was excluded due to pregnancy (n = 1)

Lost to follow-up
- Only attended 1 or 2 group sessions due to own or family disease (n = 2)
- Did not return questionnaire at follow-up (n = 1)

Lost to follow-up
- Have migrated (n = 2)
- Did not return questionnaire at follow-up (n = 2)

Analysed (n = 30)

Analysed (n = 20)
No significant differences were found between or within groups before intervention or 1 year after in terms of the degree to which TSRQ identified reasons for healthy diabetes behavior as autonomous, controlled or a-motivated. There was also no significant increase in the relative autonomy index (Table 7.1).

**Figure 7.4**
Perceived competence in managing diabetes measured by Perceived Competence with Diabetes (PCD) before and one year after Guided Self-determination Group Training (GSD-GT). Possible scores: 3-21. Scores are individual.

Scores on perceived competence showed that GSD-GT patients rated themselves as having become significantly more competent in managing diabetes at the 1-year follow-up (paired difference 5 negative; 23 positive; 2 ties; p< 0.01) compared to the control group (4 negative; 11 positive; 5 ties; n.s.) (Figure 7.4). We also observed a significant difference in perceived competence between the groups at the 1-year follow-up, with a mean rank in GSD-GT of 28.93 compared to 20.35 in the control group (p<0.05).
<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th></th>
<th>1 year follow-up</th>
<th></th>
<th>1-year difference between groups</th>
<th>Chronbach's alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GSD-GT group</td>
<td>Control group</td>
<td>GSD-GT group</td>
<td>Control group</td>
<td>Mean (CI)</td>
<td>Danish version</td>
</tr>
<tr>
<td></td>
<td>30</td>
<td>20</td>
<td>30</td>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female % (n)</td>
<td>36.80 ± 1.7</td>
<td>35.7 ± 2.1 n.s.</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Living alone % (n)</td>
<td>53.5 % (16)</td>
<td>50.0 % (10) n.s.</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>High school % (n)</td>
<td>33.3 % (10)</td>
<td>50.0 % (10) n.s.</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Unemployed % (n)</td>
<td>50.0 % (15)</td>
<td>30 % (6) n.s.</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Age at onset of diabetes (y)</td>
<td>18.2 ± 2.0</td>
<td>13.0 ± 2.2 n.s.</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Baseline HbA1c</td>
<td>9.01 % ± 0.2</td>
<td>9.05 % ± 0.2 n.s.</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Insulin U/kg/day</td>
<td>0.72 ± 0.04</td>
<td>0.81 ± 0.04 n.s.</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Perceived autonomy support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HCCQ (5-35)</td>
<td>-</td>
<td>-</td>
<td>30.7 ± 0.8 **1)</td>
<td>-</td>
<td>-</td>
<td>0.85</td>
</tr>
<tr>
<td>Group training recalled</td>
<td>-</td>
<td>-</td>
<td>26.9 ± 1.2</td>
<td>23.5 ± 1.5</td>
<td>28.9 ± 1.0</td>
<td>0.82</td>
</tr>
<tr>
<td>Visits outpatient clinic</td>
<td>-</td>
<td>-</td>
<td>26.9 ± 1.2</td>
<td>23.5 ± 1.5</td>
<td>28.9 ± 1.0</td>
<td>0.82</td>
</tr>
<tr>
<td>Type of motivation TSRQ</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autonomy (8 - 56)</td>
<td>46.7 ± 0.9</td>
<td>45.3 ± 1.9</td>
<td>47.6 ± 1.2</td>
<td>45.2 ± 1.7</td>
<td>2.4 (-1.7, 6.4)</td>
<td>0.81-0.82</td>
</tr>
<tr>
<td>Control (9 – 63)</td>
<td>34.7 ± 2.4</td>
<td>33.3 ± 3.1</td>
<td>34.1 ± 2.3</td>
<td>34.8 ± 2.2</td>
<td>-0.7 (-7.4, 6.0)</td>
<td>0.87</td>
</tr>
<tr>
<td>Amotivation (4 – 28)</td>
<td>8.6 ± 1.0</td>
<td>9.2 ± 1.1</td>
<td>8.1 ± 1.0</td>
<td>9.9 ± 0.9</td>
<td>-1.7 (-4.5, 1.1)</td>
<td>0.76-0.78</td>
</tr>
<tr>
<td>Index (Autonomy- Control)</td>
<td>12.00 ± 2.33</td>
<td>12.05 ± 2.63</td>
<td>13.50 ± 2.47</td>
<td>10.40 ± 1.78</td>
<td>3.10 (-3.7, 9.9)</td>
<td>-</td>
</tr>
<tr>
<td>Self monitored BG last week</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median (interquartile range(iqr))</td>
<td>8.0 (1.5 – 20.0)</td>
<td>8.5 (2.0 – 20.0)</td>
<td>20.0 (5.0 - 27.0)**1)</td>
<td>10.0 (2.0 – 24.0)</td>
<td>n.s.</td>
<td>-</td>
</tr>
<tr>
<td>Perceived competence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PCD (3-21) Median (iqr)</td>
<td>17.5 (14.8 – 19.0)</td>
<td>15.0 (11.25 – 18.0)</td>
<td>18.00 (16.75-20.00)**1)</td>
<td>16.50 (15.00-18.75)</td>
<td>Sig. 0.04*</td>
<td>0.78-0.81</td>
</tr>
<tr>
<td>Diabetes related problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>PAID Total(20-100)</td>
<td>32.0 ± 3.4</td>
<td>40.9 ± 4.0</td>
<td>25.6 ± 2.7*1)</td>
<td>36.7 ± 4.5</td>
<td>-11.1 (-21.0; -1.1)*</td>
<td>0.94</td>
</tr>
<tr>
<td>Emotional-related (0 – 60)</td>
<td>21.8 ± 2.5</td>
<td>27.2 ± 3.0</td>
<td>18.3 ± 2.1</td>
<td>24.9 ± 3.3</td>
<td>-6.6 (-14.6; 1.4)</td>
<td>0.93-0.94</td>
</tr>
<tr>
<td>Treatment-related (0 – 15)</td>
<td>4.2 ± 0.7</td>
<td>5.6 ± 0.6</td>
<td>2.5 ± 0.5*1)</td>
<td>4.0 ± 0.7</td>
<td>-1.5 (-3.2; 0.2)</td>
<td>0.63-0.69</td>
</tr>
<tr>
<td>Food-related (0 – 15)</td>
<td>4.2 ± 0.6</td>
<td>6.0 ± 7.2</td>
<td>3.4 ± 0.5</td>
<td>4.9 ± 0.7</td>
<td>-1.5 (-3.2; 0.2)</td>
<td>0.66-0.68</td>
</tr>
<tr>
<td>Social support-related (0 – 10)</td>
<td>1.8 ± 0.4</td>
<td>2.1 ± 0.4</td>
<td>1.8 ± 0.3</td>
<td>2.9 ± 0.6</td>
<td>-1.5 (-2.8; -0.2)*</td>
<td></td>
</tr>
</tbody>
</table>

Data are means ± SE unless otherwise indicated. Difference within GSGT group *1)p< 0.05%, **1)p< 0.01%; Difference between groups *p< 0.05%, ** p< 0.01%.
Total PAID scores decreased significantly in the GSD-GT group from a baseline level of 32.00 ± 3.4 to 25.6 ± 2.7 at the 1-year follow-up (p< 0.05), (Table 7.1). All PAID subscales showed a decreasing tendency; a significant decrease was achieved in the treatment-related subscale. Compared with the control group at the 1-year follow-up, GSD-GT patients had significantly lower total scores on PAID and on the subscale related to social support.

Figure 7.5
Frequency of self-monitored blood glucoses (SMBG) per week, before and one year after Guided Self-determination Group Training (GSD-GT). Median is marked.

The GSD-GT group’s median frequency of SMBG rose significantly from 8.0 per week before study entry to 20.0 one year after, (paired differences: 5 negative; 23 positive; 2 ties; p = 0.001) (Figure 7.5) compared to the control group’s frequency of SMBG which remained largely unaffected, with a median of 8.5 per week before and 10.0 one year after (paired differences: 4 negative; 10 positive; 6 ties; n.s.). SMBG differences between groups at one-year follow-up were not significant.

Repeated measurement ANOVA identified an overall significantly lower A1C level 3-12 months after intervention in the GSD-GT group than in the control group (difference = 0.41%; p< 0.0099) (Figure 7.6).
7.6. A1C values before and one year after GSD group training.

<table>
<thead>
<tr>
<th></th>
<th>Baseline*</th>
<th>3 mths.</th>
<th>6 mths.</th>
<th>9 mths.</th>
<th>12 mths.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A1C</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Mean Jan. 1999 - June 2000 incl. at randomisation</em></td>
<td></td>
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</tbody>
</table>

**Discussion**

Overall our results confirmed that GSD-GT initiated autonomy support was effective, enabling patients in persistent poor glycaemic control to improve their self-management over 1 year as measured by increase in perceived autonomy support from health professionals, higher frequency of self-measured blood glucoses, increase in felt competence in managing diabetes, fewer diabetes-related problems and improved glycaemic control. Our results confirm our hypotheses of the impact of guided self-determination (Figure 7.2)\(^21\). The reliability of the Danish versions of the applied measurements was good according to results of Chronbach’s \(\alpha\) (Table 7.1).

The increase in perceived autonomy support during GSD-GT, as recollected by patients one year after, was interpreted as an output result, confirming that GSD-GT initiated autonomy support had taken place as intended. The higher autonomy support perceived by GSD-GT patients 1 year after training also included professionals in out-patient clinics who were not trained GSD users. Patients probably learned during intervention to appreciate and expect this autonomy support and thus increased their ability to form autonomy-supportive relationships with professionals.

The expected link between autonomy support and autonomous motivation was not clear, as despite moving in the right direction the TSRQ autonomy index did not increase significantly in the GSD-GT-group or in relation to the control group (Table 7.1).
Taking the small study group into consideration, the possibility of a Type-2 error (overlooking a true effect due to a limited sample size) cannot be excluded. The 21-item TSRQ scale was considered to be too broad for the current intervention as it did not address the primary goal of GSD-GT, which was to motivate all participants for self-determined glucose regulation. We assume that a version of the TSRQ designed to measure motivation for glucose control would have been required to measure changes in this motivation. We also counted the fact that GSD-GT participants maintained a considerable and significant increase in SMBG one year after GSD-GT as a sign that internal motivation for glucose control had increased.

The qualitative intervention study prior to the quantitative study showed that the worksheets enhanced patients’ awareness of and ability to express, pose, assess and solve personal difficulties in living with diabetes. Effective identification of person specific difficulties and reflecting on them mutually using ‘dynamic judgment building’ (WS 4a-b) seemed to be central for the participants’ development of Balanced Self-Determinism (BSD), the ability to exercise their rights without denying the rights of others, which is a central goal for life skills training. Overall, total PAID scores indicated that GSD-GT patients had improved their problem solving skills and conflict solving skills. Subscales of PAID specified that improvements were related especially to treatment-related issues and issues related to social support (Table 7.1).

Reaching self-determined A1C goals was considered a hallmark of competence in managing diabetes and according to the patients’ worksheets, they all aimed to decrease their A1C. The overall difference (0.41%) in A1C between the GSD-GT group and the control group during the first year after intervention indicates a modest, though fairly long-term, effect of GSD-GT on patients with persistently high A1C.

A connection between self-determined glucose-control and the perception of fewer problems with diabetes is supported by a qualitative meta-synthesis of 38 qualitative studies. It concluded that patients assumed responsibility for management of their illness as a way of balancing disease-management and a normal life. Self-concordant goal-setting has been connected with higher goal attainment and higher well-being reaped from goal attainment.

A Dutch pilot study, which is not fully comparable with ours in terms of selection criteria, randomization and the definition of “persistent poor glycaemic control”, reported 6-month results of an 0.8% decrease in A1C and a borderline improvement on PAID scores matching our results. We are not aware of other intervention studies investigating the effect of autonomy support in the care of adults with persistent poor glycaemic control of Type 1 diabetes. A randomized
controlled study of mixed groups of Type 1 and 2 diabetes patients showed a 3-month effect from empowerment-based group training on A1C and self-efficacy. Coping skills group training of adolescent Type 1 diabetes patients showed a 12-month effect on A1C in a randomised controlled study.

**Conclusion**

In summary, our results confirmed that GSD applied by patients and diabetes nurses in group-training was effective in improving competence in managing diabetes, including A1C, over a period of 1 year. GSD is a worthy candidate for further development, investigation and dissemination.

**Acknowledgement**

We would like to thank Mogens Erlandsen, Department of Biostatistics, Aarhus University, for performing repeated measurements on A1C values. Our work was supported by grants from the Danish Health Insurance Foundation, 22/060-97, 22/232-98 and 22/D240-99, Novo Nordisk, Ely Lilly, the Research Initiative in Aarhus, the Danish Nurses’ Organization and Aarhus University Hospital.
Reference list


Chapter 8

General discussion of method
8.1. Introduction

This study set out to test the hypothesis that the effectiveness of relational problem solving in difficult diabetes care would increase if the currently applied methods were replaced by methods known to be consistent with empowerment and having the apparatus required to overcome barriers in relational problem solving.

An initial interpretation of the problem was conducted through three interrelated grounded theory studies (Chapters 3-5). A synthesis of the findings from these studies was conducted resulting in the development of GSD, with further development completed through participatory research in busy clinical practice. A qualitative evaluation of the applicability and clinical significance of GSD was performed in one-to-one settings as detailed in Chapter 6, which also describes the transition of GSD to group-settings in preparation for a quantitative evaluation. The effect of GSD in group-settings tested in RCT is described in Chapter 7.

This chapter will discuss the strengths and weaknesses of the design and methods in the study as described in these chapters.

8.2. Intervention developed on the basis of qualitative research

‘Real world’ research\(^1\) was considered necessary as conditions in a busy interdisciplinary team were assumed to be part of the problem for relational problem solving. The specific research design was ‘programmatic qualitative research’ as the intervention was based on qualitative findings, which were subsequently evaluated qualitatively and quantitatively.

\[\text{Researchers may indeed move directly from the development of grounded theory of an event to the application and qualitative and/or quantitative evaluation of an intervention derived from qualitative research}^{2} \text{ p.220}\]

This design has been recommended by Sandelowski as a way of ensuring that a programme will be perceived as being meaningful for those invited to participate. I had confidence in the ability of qualitative research to reveal processes and barriers which were normally concealed by some of my own profession’s blind spots. The method used in the initial phase was grounded theory\(^3;4\). The design functioned well and a fruitful interaction took place when knowledge derived from the grounded theory studies and the nurses’ clinical experience were exchanged. As Glaser and Strauss...
have emphasized, the person who applies any given theory will in turn become a generator of theory and the theory will go on to become an *ever-developing entity*\(^4\), p. 242.

Glaser and Strauss’s four criteria for testing the quality of grounded theories (‘fit’, ‘work’, ‘relevance’ and ‘modifiability’) were acknowledged with ‘fitness’ seen as a matter of correspondence to facts in social reality\(^5\). I regarded myself as being critical of my own and participants’ perceptions of our ‘real world’ but I also regarded myself as being in a well organised research situation in which my possibilities for discovering blind spots were better than participants’. In consistency with a grounded theory approach\(^6\) I thus perceived myself as having responsibility for data interpretation and this was why I, for instance, first wrote the analysis before asking nurses and patients if my interpretations were meaningful for them. Two years of participatory research and the qualitative intervention study also provided good opportunities for evaluating the ‘work’, ‘relevance’ and ‘modifiability’ of the grounded theories and GSD.

During every phase the study (Chapter 2 p. 22) critically questioned my own, the patients’ and the professionals’ assumptions about difficulties in improving care, and the study is therefore regarded as critical research. According to Sandelowski\(^7\), critical research need not be uniformly linked to either methods or techniques “so clinical trials for example are not precluded in critical theory research”.

The fact that intervention takes time\(^8\) was acknowledged by prioritising a two-year period for participatory implementation and in addition subsequently conducting a qualitative evaluation in order to confirm in detail that the intervention was working as intended. The difficulties of conducting a valid qualitative evaluation of a method one has oneself created (Chapter 6, p.105) were considered before the qualitative intervention study. I therefore endeavoured to ensure the necessary distance and keep a clear focus during the evaluation and was supported in this by the same critical issues that had been defined prior to the grounded theory study (Chapter 2, p 22). Factors which were identified in the grounded theory study as effective but which had rarely been seen in traditional care and had therefore been inadequately studied (Chapter 6, p. 91) were more pronounced in the intervention study. This provided the opportunity to study these processes and their positive consequences such as *co-created knowledge*. The *releasing* property of *co-created knowledge* was discovered in this way.

Denzin and Lincoln have claimed that qualitative researchers are more likely than others to confront the everyday in their research and see the world in action. They may, however, be
wrong in claiming that qualitative researchers thereby succeed in ‘embedding’ their findings in this world.

“Qualitative researchers are more likely than quantitative researchers to confront the everyday social world. They see this world in action and embed their findings in it.”\textsuperscript{9} p. 10.

Morse has, for instance, argued that more attention should be paid to the use of the results from qualitative research and less attention to “doing” the research. Morse suggests that there is a need to have some “hard edges” on how qualitative research is described. It is seen as a strength that the current study started out qualitatively\textsuperscript{10}, but also as equally necessary that a process of ‘hardening the soft data’ took place during the development, implementation and evaluation of GSD.

The ‘hardening’ of soft data may serve as a metaphor for the research process from grounded theory to randomised controlled study\textsuperscript{11}. The hardening process comprised many steps from the time when the first ideas were formed in the grounded theory analysis through the point when patterns of concepts proved consistency and were recognised and supported by both nurses and patients, till the intervention was accepted and carried through, the expected changes appeared, validated scales were chosen and the expected changes were measured, proving the effect of the intervention.

\textbf{8.2.1. Theoretical saturation}

Procedures for sampling in the qualitative and quantitative parts of the study took into account the very different purposes and premises on which these studies were based. It could be claimed that it was necessary to have more than 11 dyads in the grounded theory study (Chapters 3-5) and more than 2 pilot, 2 non-completing and 7 completing dyads in the qualitative intervention study (Chapter 6, p.103). These numbers were, however, considered sufficient partly because theoretical saturation was considered to have been reached and partly because the findings in the two studies were consistent with each other.

\textbf{8.3. Group training and randomised controlled trial}

The idea of transforming GSD into group-settings and conducting a randomised controlled trial occurred after the clinical significance of GSD had been confirmed qualitatively in one-to-one settings. Group training was regarded as an appropriate setting, as it would allow GSD to be
provided at lower cost in future and was at the same time an appropriate setting for testing the effect of GSD. The randomised controlled design was selected, as it was considered that it would provide the most valid information of the effect of GSD and the qualitative intervention study had shown that the conditions for conducting such a trial were obtainable. An “on-off” situation could be obtained, as it seemed that a pattern interruption would only take place in relational problem solving if the worksheets were used. This provided a possibility for separating an intervention group from a control group in the same diabetes unit and conducting randomisation at an individual level.

The theory behind GSD and consistent changes in the patients’ health behaviour observed in the one-to-one settings pointed at specific measurements for testing effect (Chapter 2, p. 24, Chapter 6, p. 121, Chapter 7, p. 132 and Appendix E, p. 244). Translation into Danish followed international recommendations and satisfactory internal reliability was obtained (Table 7.1, p.136). The answers from 25 experienced Type 1 diabetes patients confirmed the face validity of the Danish versions. The measurements selected were in accordance with Glasgow et.al’s recommendations for evaluating programmes with more standardized and objective measures of diabetes management behaviours (TSRQ was used) and measuring self-efficacy (PCD was used) and patient-provider interaction (HCCQ was used), quality of life and patient-functioning outcomes (PAID was used).

**8.3.1. RCT as a theory driven intervention**

Sedani and Braden have recommended a theory-driven approach to effectiveness studies over outcome-focused effectiveness research because it provides researchers and clinicians with a clearer explanation of the problems encountered in effectiveness research. Sidani and Braden stress that such a framework is comprehensive and depicts the complexity of real life, in which multiple factors affect the achievement of the outcomes expected of an intervention programme. The framework therefore incorporates multiple variables, both theoretical and practical, that contribute to the intervention effects.

An intervention theory will, according to Sedani and Braden, comprise both descriptive and prescriptive elements: the descriptive element presents the problem as well as the processes that produce the problem while the prescriptive element describes the causal processes through which the intervention is expected to produce the desired outcomes, the specific changes expected as a result of the intervention and the conditions under which these causal processes will arise. As
appears clearly from Table 6.1 (Chapter 6, p. 96-101), GSD comprises both descriptive and prescriptive elements and can thus be argued to be an intervention theory.

For an intervention theory to be useful in guiding the design of the intervention, it has to address the following elements: the problem for which the intervention is given, the critical inputs, the mediating processes, the expected outcomes, the extraneous factors, and the implementation issues\(^\text{13}\) p. 44.

Following the above argument, it can be claimed that a study designed as programmatic qualitative research\(^2\) can comprise theory-driven evaluation as recommended by Sidani et al. and that the RCT evaluating the effect of GSD group training represents such a theory-driven evaluation.

GSD addresses many of the elements that an evaluation theory according to Sidani et al. has to address. The problem that motivated the intervention was addressed through qualitative studies using grounded theory methodology, which consciously aimed at developing theories that were able to provide an interpretive explanation of a problem\(^2,3,14,15\). The critical inputs and the ‘dosage’ needed by people with Type 1 diabetes in persistent poor control were identified in the grounded theory study (p.91), extended through participatory research (pp. 94-95) and confirmed through the qualitative intervention study (pp.106-122). The mediating processes were known from both participatory research and the qualitative intervention study, which also prevented a so-called type 3 error (Chapter 6 p. p105)\(^{13}\). The expected outcomes of GSD in one-to-one settings were known from the qualitative intervention study.

### 8.3.2. Statistical considerations

The reliability and internal consistency of the Danish versions of the scales applied were tested using Chronbach’s \(\alpha\)\(^{16}\) (Table 7.1). As HCCQ, TSRQ and PAID data fell within normal distribution ranges it was decided to test significance of differences by using t-tests for independent groups and the t-test for paired data.

Data on PCD and the frequency of weekly SMBG were, however, not distributed normally and significance was thus tested by using non-parametric tests, the Mann-Whitney test for independent groups and the Wilcoxon signed rank test for paired data. The A1C data were analyzed by means of a repeated measurement ANOVA allowing for both inter- and intra-individual random variation using Proc Mixed in SAS v 8.2. P-values < 0.05 were considered statistically significant.
8.4. GSD in one-to-one compared with group-settings

It was not the intention to compare the effectiveness of GSD in one-to-one and group settings due to the limited number of participants. The number of patients per professional in GSD group training was limited (3-4) because of the close coaching each participant required. This meant that a group size of 10 patients and 3 professionals was appropriate. Half as many hours were thus used in group training than in individual training. While the individual training appeared to be more intense, group training was valued for the possibility of meeting other people with diabetes (Appendix E). Only three patients invited for the RCT refused to participate because of the group-setting but several patients in the one-to-one setting also mentioned that they would not have dared to participate in group-training from the beginning.

The number of worksheets used was high because of the complexity of diabetes in persistent poor glycaemic control. This was commented on in group training but appeared, however, to be less problematic in one-to-one-settings probably because it was easier to take consideration of individuals here than in a group setting.

8.5. Non-participation

As mentioned earlier (Chapter 2, p. 24) patients were invited in two stages in order to secure an appropriate number of participants in the RCT: The first invitation was sent to patients with average HbA1c ≥ 8.5 and the second was sent to patients with average HbA1c < 8.5 and ≥ 8.0%.

Only 32% from the first group and 29% from the latter group agreed to participate in group training and 16 (21%) of those who had accepted failed to show up at randomisation. The main reason for not participating was lack of time (Appendix A, Table A2.) In order to reach some of the 75 % we did not reach in this intervention, recruiting strategies other than written invitations could be considered. For example, face to face and phone invitations were accepted by all but one of the patients in the qualitative intervention study.

8.6. Limitations of the study

The study did not compare the effectiveness of GSD in a one-to-one setting and in a group setting. In the RCT it would have been optimal to have two control groups; one receiving traditional care and one receiving non-specified group training. This would have provided us with information about whether some of the effect shown in the GSD group was due to just meeting in groups. It would also have provided us with qualitative information about whether patients who had been
prepared by means of using worksheets got to know each other more easily because they were patients in the GSD group. Two control groups would have made it possible to test both hypotheses.
### Summary on the methodological aspects of the GSD approach

#### Design
- Qualitative programmatic research provided an interpretative explanation of barriers to effective relational problem solving in usual care as detailed in three interrelated grounded theories.
- GSD was developed in consistency with grounded theory findings as a link between description and prescription. It can thus be regarded as an intervention theory.
- Participatory research ensured that GSD was acceptable and applicable by patients and professionals in a ‘real life’ situation of clinical practice.
- Qualitative evaluation of GSD in one-to-one settings provided information on the processes in which GSD caused changes and confirmed GSD’s consistency with the grounded theory findings and its ability to create the intended changes.
- Quantitative evaluation in RCT provided information on the probability of significant effect when using GSD in group-settings.

#### Intervention
- GSD is a theory driven intervention based on grounded theories and formal theory and the intended effect has been verified clinically in one-to-one settings.
- The skills needed to use GSD are known from supervision of nurses.
- GSD intervention is well known from qualitative study.
- The robustness of GSD is known from both one-to-one settings and group settings.

#### Questionnaires
- The application of validated instruments with content validity consistent with GSD intervention and translated in accordance with recommended guidelines ensured a high validity of the questionnaires.

#### Sampling
- Theoretical sampling in the qualitative studies. Theoretical saturation decided sample sizes.
- Patients invited to participate according to well-defined criteria for inclusion or exclusion and were randomised at the individual level.
- No patients from qualitative intervention phases were invited to participate in the RCT.

#### Strategies for recruiting patients
- Face-to-face invitations or invitations by phone were used in the qualitative evaluation of one-to-one settings.
- Written invitations were used in the quantitative evaluation of group-settings.

#### Statistical tests
- Chronbach’s α; t-tests for independent groups and the t-test for paired data; Mann-Whitney test for independent groups; Wilcoxon signed rank test for paired data; repeated measurement ANOVA.

#### Generalisation
- Grounded theories can be generalized for patient-provider relationships in diabetes care and other chronic care settings.
- General applicability of GSD in similar settings and shared care settings.

#### Limitations of the study
- The study did not compare GSD in one-to-one settings and group-settings and thus only provided vague insights into the advantages and disadvantages of the two settings.
- The study did not provide information about the difference between group-settings without and group-settings with GSD, which might have determined which part of the outcome could be ascribed to the group experience.
Reference list

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Chapter 9

General discussion of results
9.1. Introduction

The study focused on testing the hypothesis that:

*The effectiveness of relational problem solving to develop patient self-management in difficult diabetes care will increase if current methods are replaced by methods known to be consistent with empowerment and having the apparatus to overcome barriers in the context of difficult diabetes care.*

and achieving the aims stated in the general introduction (Chapter 1, p.4).

Guided self-determination (GSD) was developed on the basis of three interrelated grounded theories detailed in Chapters 3-5. The theories explain difficulties and possibilities seen in current care for obtaining effective relational problem solving between patients and professionals in difficult Type 1 diabetes. Among the apparatus included in Guided Self-Determination to overcome the barriers identified are factors rarely used in current care but identified as playing an active role in increasing the effectiveness of relational problem solving (Chapter 6, p. 91).

9.2. Barriers to effective relational problem solving

The methods normally used in relational problem solving appear to represent ways in which we as health care professionals seek to solve the dilemma of not knowing what the true difficulties are for the person we meet and having limited time to find out. As expected, this dilemma was dominant in the care of patients with long-standing Type 1 diabetes and poor glycaemic control.

Barriers to effective relational problem solving were identified at three levels: patient-provider perspectives, relationships and communication, as discussed in Chapters 3-5. *Conflicting life-disease perspectives* were addressed in GSD intervention by specifying that the scope of problem solving included *person-specific difficulties* in living with diabetes. A change in patient-provider relationships was accomplished by inviting patients to form *I-you sorted relationships* (explicitly stating that both parties’ knowledge and experience was necessary and legitimising different points of view and difficult feelings) during problem solving. *Zone 5 communication* and *level III-IV reflection* were promoted through semi-structured worksheets (Chapter 6, pp. 93 and 96-101).
9.3. Bridging life and disease

GSD in one-to-one settings proved able to overcome the barriers mentioned above and resulted in **person-specific knowledge** of difficulties lived with diabetes being co-created more quickly and more frequently than before.

The increased frequency of **co-created knowledge** of person-specific difficulties allowed further study and it was proved to have a four-stage releasing effect: releasing knowledge in the mind, in a supportive relationship, in a team and in daily life (Chapter 6. p. 112). Corresponding to these stages, a potential for change was released and resulted in the tendency to keep life and disease apart being transformed into one of bridging life and disease (Chapter 6. p.138). As a consequence, patients increased their ability to solve problems and conflicts in daily life with diabetes. They communicated more openly and honestly about their illness and developed self-determined motivation for monitoring blood glucoses. GSD thus proved to be clinically significant in one-to-one settings and dissemination in group-settings (at a lower assumed cost) was prepared.

One-year results of RCT testing GSD in 16-hour group training (GSD-GT), showed that intervention patients did better than control patients in terms of self-management as measured by increase in perceived autonomy support from health professionals, perceived competence in managing diabetes and frequency of self-measured blood glucoses and decrease in diabetes-related problems and A1C level over 1 year (Chapter 7).

The results from qualitative and quantitative research thus both showed that GSD increased the effectiveness of relational problem solving in difficult Type 1 diabetes in one-to-one settings as well as in group settings.

9.3.1. Pattern interruption needed in relational problem solving

Through the development, implementation and evaluation of GSD it became clear that GSD used as a method provided a pattern interruption in difficult diabetes care, which challenged and changed the usual ways of thinking and acting in relational problem solving (Figure 9.2).

My assumptions about powerful professionals and powerless patients were in some degree turned upside down in the descriptive study, as patient resistance represented a kind of power with sometimes astonishing strength, which professional power appeared unable to cope with (Chapter 3, p. 36-38). This made professionals appear quite powerless. The study showed that professionals obviously wanted to help patients but that patients did not always recognise this. It
thus appeared to be certain that both professionals and patients were frequently disempowered in relational problem solving.

**9.3.1.1. Person-specific knowledge destroys the compliance illusion**

The descriptive part of the study also confirmed findings made in qualitative research\(^3\)-\(^5\) that professionals tend to act with a compliance expecting approach and to take responsibility for problem solving rather than practicing autonomy supportive problem solving. The poor outcome of a compliance expecting approach\(^6\),\(^7\) was also confirmed.\(^8\) The intervention study, however, showed that it was possible to change compliance-expecting approaches by providing a method through which patients were prepared to take an active role in problem solving.

**9.3.1.2. Time used in another way**

Written communication was used in another way than before and showed possibilities we had not been aware of previously, though some examples were known\(^9\). Limited time\(^4\) was also viewed in another light. The importance of a patient’s *time to think* was acknowledged and consequently the time *between* and *before* conversations became more important as did giving the patient something to think about. Time was thus used as a fellow player and not as an adversary.

**9.4. GSD compared with existing literature**

Overall this project has designed GSD to be a method consistent with empowerment\(^10\)-\(^12\) and with a greater ability than traditional methods to provide autonomy support\(^2\) in relational problem solving and start a process of developing life skills\(^13\) with diabetes (Chapter 1, p.10).

The methods used in relational problem solving have frequently been questioned and criticized. In nursing, for example, attention has been called to the danger of using pre-formulated nursing diagnoses, which may have a negative and destructive effect in relational problem solving by, for instance, labelling patients as ‘non-compliant’\(^8\). National organisations such as nursing organisations, have been recommended to be aware of the paternalistic underpinnings of diagnostic processes\(^14\). The danger that diagnostic systems can deprive professionals and patients of the judgment needed in health care situations has been pointed out by Powers\(^15\). Many years ago Henderson called attention to the importance not only of the construction of methods but also of their titles, which might in themselves impede interdisciplinary collaboration\(^16\),\(^17\).
9.4.1. GSD as a life skills approach

Findings were consistent with the hypothesis that methods such as diagnostic methods in nursing and medicine are counter-productive to empowerment and thus provide some of the reasons for why empowerment has not been realised in practice. Even though attitudinal changes can be accomplished by attending courses, it is assumed that this change will in part be negated if professionals return after a course to practice work in which provider-dominant methods are still being used.

Paterson has called for a revised conceptualisation, which acknowledges the uniqueness and complexity of authoritative knowledge as the basis of patients’ self-care decision-making. The co-creation of separate person-specific knowledge as a consequence of using GSD in the current study appeared to indicate that a life skills approach might be such a new conceptualisation involving methods developed for patients rather than for professionals.

Life skills have been defined as problem-solving behaviours appropriately and responsibly used in the management of personal affairs and personal affairs have been connected with five areas: self, family, leisure, community and job. In selecting issues to work with, patients in the qualitative intervention study frequently addressed these areas. Monsen has presented an important developmental distinction between two ways that human beings can stand out from the mass, by being either an individual or a person and this distinction was influential in the study. Individuals differentiate themselves from the mass by wanting merely to show that they are different to others, while persons see a purposeful meaning in standing out from the mass because something has to be done and they are the ones to do it. In chronic care these thoughts are considered to be useful, as we are obliged to support people with chronic illnesses to live a meaningful life. In the study, getting to know the patient as a person was achieved through co-creating person-specific knowledge. Such knowledge involved knowing how the person wanted to interact with the world, what he or she considered, weighed, pondered, appreciated, appraised, wished to dissociate him or herself from, intended to do and so on.

9.4.1.1. Balanced self-determined glucose control

In the study autonomy is used in the life philosophy sense to stress that people have choices and possibilities in their lives. In the study patients whose motivation had mostly been other-determined began to behave more autonomously. Curiosity, openness and honesty about glucose control began to develop during the GSD course. As Dewey has stated, curiosity is important for growth but very
Reviving curiosity appeared especially to be important in the process of changing motivation for self-monitored BG control. Participants in the qualitative intervention study revealed the ways they had previously reacted when they had not measured BGs for an outpatient visit. They cancelled appointments, turned up without BG results or turned up with BG results that they had made up for the appointment (Chapter 6, p.110). They did not therefore benefit from professionals as they either did not meet or were involved in problem solving on the basis of non-existent or false information about their own glucose control. Patients with high blood glucose are known to stay away from out-patient clinics and have few expectations regarding health care professionals. A link between failed self-measurement of blood glucoses and low frequency of attendance at out-patient clinics was thus suggested.

9.4.1.2. Dynamic judgment building
Dynamic judgment building (Chapter 1, p. 11) seemed to fit very well with life skills theory. It was in fact considered to be the core of GSD, meaning that patients who had not completed WS 4a and 4b had not really been using GSD. Bos has emphasised that people who have used dynamic judgment building mention the “life character” of the model. Furthermore, a short definition of life skills training also bears some resemblance to dynamic judgment building, being defined as “the treatment of choice.”

9.4.1.3. The Stages of Change theory
As mentioned in Chapter 1 (pp. 12-13) the trans-theoretical stages of change theory formed part of GSD in the form of a screening instrument (WS 3a and 3b) to provide self-determined choice and a quick overview for both patients and professionals of the patient’s need for and readiness to make changes. A similar purpose is aimed at in another form in an instrument called the Agenda Setting Chart which is combined with a Readiness to Change Ruler created for Type 2 diabetes patients in general practice. Although GSD, as previously mentioned, covers many of the change processes in the stages of change theory, it best addresses the following: consciousness raising, dramatic relief, environmental re-evaluation, self re-evaluation, self-liberation and helping relationships. It can be argued that GSD thus covers all of the stages of change from pre-contemplation to maintenance.

In addition, one strength of GSD is its ability to identify change strategies, which it is important to distinguish from change processes because of their unique and person-specific character.
9.4.1.4. Generalised knowledge not enough to integrate diabetes

The value of an integration paradigm in diabetes care instead of a compliance paradigm has been suggested by Hernandez. Helping people to reach a stage called “The science of one” can be compared to the GSD intervention goal of promoting a process of connecting life and disease through co-creating person-specific knowledge. The psychological aspects of the many skills seemingly instrumental in diabetes care has also been emphasised by Strauss.

The very important fact that generalised knowledge is not enough to accomplish change was also stressed by the patients, many of whom were aware that they had plenty of knowledge which they did not use. As stated before, a direct route between diabetes knowledge and improved diabetes behaviour cannot be assumed.

9.4.2. Methods for future

GSD appears to belong to a new generation of methods which have been developed recently in teaching and counselling. It constitutes a frame, open for a separate person specific potential for change to be revealed and exploited in acknowledgment of the necessity to perceive health as an open concept.

The motivation to develop worksheets came from the fact that patients in the grounded theory study on the one hand appeared to be bored and on the other hand appreciated having time to think. Arborelius had been developing health education models for almost twenty years and three of these were included in GSD (WS 4c-e, Appendix D).

Similar methods seem to exploit the fact that “Illustrations can be worth more than ten thousand words”. Many of these methods have been characterized as ‘visual representation strategies’ for instance in the form of ‘node link mapping’. Nine of the GSD worksheets can be characterized as visual representation strategies (WS 2a, 2d, 2e and 4a-f Appendix D), as they support and represent the patient’s line of thought. Even the dynamic judgment building model created by Bos has been formed as a visual representation strategy (WS 4a-b, Appendix D).

The value of the method of listening to life stories was also acknowledged, as patients appreciated having the chance to tell their story but resented having to repeat it several times. Due to the limited time available, a short form was prepared (WS 2a, Appendix D).

Values clarification was acknowledged as an autonomy supportive way of asking questions and used in WS 2c. Drawings, metaphors and phrases were also invited (WS 2d) in order to get access to issues that patients yet not could explain in words.
The idea of doing ‘homework’ as part of a change process is well known from psychiatry but has as yet rarely been seen in somatic chronic care. Such methods make real the possibility that the diabetes team can act as a centre where patients’ unstated knowledge can in part be voiced. A few words expressed by the patients on paper can give access to whatever problem or challenge they are currently finding difficult.

9.5. Beyond Type 1 diabetes in persistent poor control

About 50% of people with Type 1 diabetes are supposed to live with poor glycaemic control and in the current study 56% of the patients assessed for eligibility had actually been living with poor glycaemic control for many years. This points to an increased risk of late complications for these patients and the necessity to intervene earlier in their lives.

The study confirmed that difficult problems, which it had not previously been possible to solve, could be solved when current methods were replaced by GSD. This gives reason to consider how GSD could be used by and developed for other patient groups inside and outside diabetes.

For example, there appear to be similar weaknesses in relational problem solving for Type 2 diabetes. This patient group is more than 6 times larger than the Type 1 diabetes group and if we assume that about 40% of these patients are living with diabetes in poor glycaemic control it becomes relevant to heed Glasgow’s words that diabetes ought to be regarded as a public health disease.

Thinking is a tool for problem solving and truth is a characterization of claims that lead to acceptable problem solving. All knowledge is, according to Dewey, considered to be temporary and in principle wrong. Dewey’s considerations of truth and problem solving imply that true thinking in individual diabetes care has not taken place if problems are not solved acceptably.
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Chapter 10

Conclusion
With reference to the hypothesis and aims of the study, the following conclusions can be drawn:

The study fulfilled its overall purpose of developing and testing a method for relational problem solving consistent with empowerment and having the necessary apparatus to overcome barriers to self-management in difficult diabetes care. Barriers were interpreted and detailed in three grounded theory studies: 1) Keeping life and disease apart, 2) Relational potential for change and 3) A model of person-specific reflection. Guided Self-Determination (GSD) was developed in accordance with these findings.

Participatory research let to the further development and implementation of GSD in busy clinical practice drawing on worksheets and advanced professional communication skills. Adjusted to Type 1 diabetes and persistent poor glycaemic control, GSD proved acceptable and applicable by patients and professionals in difficult problem solving.

A qualitative intervention study confirmed that patients with persistent poor glycaemic control and GSD-trained diabetes nurses were empowered and that the effectiveness of problem solving improved when GSD was used in one-to-one settings. Finally, a randomised controlled trial of GSD in 16-hour group training confirmed that GSD was effective and enabled people with Type 1 diabetes in persistent poor glycaemic control to form autonomy supportive relationships, increase the self-measurement of blood glucoses, develop competence in self-management, solve problems related to diabetes and improve glycaemic control.

Problems connected with diabetes in persistent poor glycemic control were more effectively resolved when the usual methods were replaced by GSD in relational problem solving between patients and nurses.
Chapter 11

Perspectives and implications for future research
11.1 Introduction

The grounded theories developed in chapters 1-3 are supposed to have general implications in relational problem solving across patient groups and professional disciplines in primary and secondary health care settings. Overall the study has confirmed the effectiveness of GSD in difficult Type 1 diabetes problem solving.

11.2 GSD-provided person-specific knowledge as the backbone in the diabetes team

GSD could be further developed, refined and adjusted to other patient groups and could be implemented across disciplines. The original idea for developing GSD was that it would be an interdisciplinary approach. The current study was not, however, designed to provide information about interdisciplinary implementation of GSD, which it is still hypothesised would be necessary in order to understand the full potential of GSD. It is nevertheless assumed that the person-specific knowledge provided through GSD would be valuable for fully exploiting the diverse competences in the diabetes team. By sharing problem solving based on person specific knowledge the specific competences of patients, dieticians, doctors, nurses and psychologists are expected to be better exploited in the team than if parallel problem solving activities take place.

- ‘Invitation to work together’ (WS1a), ‘Progression paper’ (WS1b) and ‘Important events in life with diabetes’ (WSA2) can be recommended in the standard care of Type 1 and Type 2 diabetes patients, as a way of exchanging, using and retaining person specific knowledge in small primary teams (including the patient, a doctor, a dietician and a nurse).

- The whole GSD programme in one-to-one settings or group settings can be recommended as an approach for people with Type 1 diabetes who perceive many difficulties in living with diabetes, be they well or poorly regulated.

- The study group in this thesis belonged to a group of diabetes patients who had perceived many problems for a long time. They therefore received GSD in a large ‘dose’. Other groups may benefit from a smaller dose of GSD in the form, for example, of single worksheets used in ad hoc situations.
An adjusted version of GSD can be developed for people with newly diagnosed Type 1 diabetes.

An adjusted version of GSD can be developed for young people with Type 1 diabetes who are being transferred from a diabetes clinic for children to a diabetes clinic for adults.

GSD can be adjusted to people with Type 2 diabetes, whether newly diagnosed or people with difficulties in living with the illness.

A GSD version can be developed for people lacking awareness of low blood glucose.

Nurses in specialised diabetes settings can be recommended to have a central role in these teams for achieving and exchanging person specific knowledge and retaining such knowledge in the diabetes team. To take on such a central role, nurses would require basic GSD training of about 10 lectures, specialized training in the use of GSD and continuing training in communication skills.

**11.3. Recommendations for research**

- Developing and testing a GSD programme for adolescents who are being transferred to clinics for adults.

- Large-scale multi-centre dissemination studies of GSD.

- Organisational studies of changes in diabetes teams as a consequence of introducing GSD across disciplines.

- Studies of shared care between diabetes clinics and general practitioners based on GSD for patients with difficulties in living with Type 1 or Type 2 diabetes.
Chapter 12

English summary
General introduction

The thesis consists of a general introduction followed by an overview of design and method, three qualitative articles and a presentation of the development and implementation of Guided Self-Determination and its clinical significance qualitatively studied. Subsequently a randomised controlled study is presented followed by overall discussions of methods and results and a conclusion. Finally, the results are put into perspective and directions for future research are proposed.

Chapter 1 introduced the idea that current methods in relational problem solving are counterproductive to the implementation of empowerment in clinical practice and the development of patient self-management in difficult diabetes care. In this chapter central theories are introduced. Guided Self-Determination is in this chapter connected with formal theories and it is argued that it is a link between the philosophy of empowerment and developing life skills with diabetes as a goal for individual patient care. Life skills are defined as “Those personal, social, cognitive and physical skills which enable people to control and direct their lives, and to develop the capacity to live with and produce change in their environment.” A short presentation of the development of life skills outside diabetes care and reasons for introducing the concept in diabetes care are given. Enabling people to become Balanced Self-Determined (BSD) persons defined as “individuals who are able to exercise their rights without denying the rights of others” is a goal of life skills training. Chapter 1 also argues for using Lex Bos’s method “dynamic judgment building’ and Prochaska’s stages of change theory.

Chapter 1 presents the overall purpose, hypothesis and aims of the study:

Purpose: To develop and test a method for relational problem solving which is consistent with empowerment and includes the necessary apparatus for overcoming barriers to developing self-management in difficult diabetes care.

Hypothesis: The effectiveness of relational problem solving to develop patient self-management in difficult diabetes care will increase if current methods are replaced by methods known to be consistent with empowerment and having the apparatus to overcome barriers in the context of difficult diabetes care.
The aims of this thesis were:

1. To present grounded theories derived from patient-provider interactions in difficult diabetes care
2. To detail Guided Self-Determination and describe the participatory process of developing the method
3. To illustrate how the impact of Guided Self-Determination was qualitatively determined in difficult diabetes care
4. To present the effects of Guided Self-Determination on the self-management of diabetes including glucose control
5. To discuss the results and their consequences for clinical practice and future nursing research

Chapter 2 briefly describes the research design, which was initiated by a grounded theory study of patient-provider interaction in eleven dyads concerning problems related to diabetes in poor glycaemic control.

**Development, implementation and evaluation of Guided Self-Determination**

An interpretation of the barriers to effective problem solving was provided in the form of three grounded theories detailed in Chapter 3-5.

**Chapter 3** detailed *Conflicting life versus disease priorities*. *Keeping life and disease apart* was identified as a core category involving a pattern of conflict lines between and within patients and health professionals, which disempower them in problem solving. Three approaches were identified: a *compliance expecting* approach kept the pattern unchanged, a *failure expecting* approach deadlocked the pattern and a *mutuality expecting* approach neutralized the conflict lines through situational reflection and revealed a positive potential in different points of view, which would be easy to exploit in problem solving.

**Chapter 4** detailed *Patterns of exploiting relational potential for change* A core category of relational potential for change was identified. Around this category appeared a pattern of three types of relationships named according to their way of handling I-you boundaries.
Professionals mostly shifted between two types of relationship, *I-you-distant provider-dominance* and *I-you-blurred sympathy*. A third relationship, *I-You-sorted mutuality*, was rarely seen and not yet fully evolved. The relationships differed in: a) scope of problem solving, b) roles assigned to the two parties, c) awareness of difficult feelings and different points of view and d) the quality of knowledge they achieved as the basis of problem solving. *I-you-sorted mutuality* appeared to be the most effective framework for relational problem solving in difficult diabetes care. Implications for practice and further research are discussed.

**Chapter 5** detailed Model of person-specific reflection.

Variations in approach to communicative paths and barriers were conceptualised and assembled in a person-specific reflection model specifying 1-5 zones of focusing and 0-IV levels of deepening situational reflection. Mutuality appeared to require zone-5 focusing and level III-IV situational reflection, which seldom occurred. Findings from these three grounded theory studies gave rise to the development and implementation of Guided Self-Determination (GSD).

**Chapter 6** presents a description of the development and the implementation of GSD through participatory research ensuring GSD’s acceptability and applicability in busy clinical practice. Connections between grounded theory findings and the development of specific worksheets are described in detail (page 96-101) as well as reasons why advanced professional communication was required. A qualitative intervention study is described in which GSD replaced traditional methods applied in one-to-one settings in 11 nurse-patient dyads for solving problems related to Type 1 diabetes in persistent poor glycaemic control. The clinical significance of GSD is illustrated and discussed with regard to its ability to change the difficult patterns revealed by the grounded theories. GSD caused person-specific knowledge of difficulties lived with diabetes to be co-created more quickly and more frequently than before and proved to have a four-stage releasing effect: releasing knowledge in the mind, in a supportive relationship, in a team and in daily life. As patients moved through these stages, a tendency to keep life and disease apart was transformed into one of bridging life and disease.

**Chapter 7** presents the results of a randomised controlled trial applying GSD in a 16-hour group training programme (GSD-GT) for people with Type 1 diabetes in persistent poor glycaemic control. Included were adults aged 18 to 49 years, mean HbA1c ≥ 8.0% for at least two years, onset
of disease ≤ 40 years and insulin treatment from onset. Participants were randomised in a proportion of 3 to 2 for immediate GSD-GT in 2001 (intervention group) or delayed group training one year later (control group). 50 patients (30 GSD-GT and 20 control patients) completed the study. GSD-GT patients did better than control patients in terms of self-management as measured by a) increase in perceived autonomy support from health care professionals measured by Health Care Climate Questionnaire (p<0.01); b) higher frequency of self-monitored blood glucoses (p<0.001); c) increase in perceived competence measured by Perceived Competence in Diabetes (p<0.01); d) fewer diabetes-related problems measured by Problem Areas In Diabetes (p<0.05); and e) improved glycaemic control over 1 year measured by A1C (p<0.01). Chapter 6 concludes that patients with persistent poor glycaemic control experienced improved self-management of Type 1 diabetes and A1C one year after applying GSD in a group-training programme. GSD was judged to be a worthy candidate for further development and investigation.

General discussion, conclusion and perspectives

Chapter 8 discusses the design and the methods applied in the other chapters. The design applied can be characterized as a combination of two designs: programmatic qualitative research and theory driven randomized controlled trial. The chapter discusses the advantages of basing an intervention on qualitative findings as a way of ensuring that the content of an intervention fits the needs of the participants, improves the possibility to interpret the results and increases the applicability of the results. Finally weaknesses and study limitations are described.

Chapter 9 discusses the results of the study and emphasizes that GSD according to the qualitative intervention study managed to cause a pattern interruption in relational problem solving between patients and professionals. The patients’ time before and between conversations was used constructively and the idea of ‘compliance’ appeared to be an illusion when person-specific knowledge was co-created. The pattern interruption was also identified in the group-training and possible to measure one year after a 16 hour group-training program. GSD is seen as part of a new generation of methods developed recently and assumed to be effective in promoting self-determined behavior change.

Chapter 10 presents the conclusions. Qualitative and quantitative research confirmed that GSD was a clinically and statistically effective approach for overcoming barriers in traditional relational
problem solving and had proved to be acceptable, applicable and effective across different settings and different research strategies.

Chapter 11 puts the study results into perspective and points to the essential implications of the study. Selected parts of GSD are recommended as a standard approach for all Type 1 and 2 patients. GSD in its current version is recommended for Type 1 diabetes patients with perceived difficulties in living with diabetes while adjusted versions of GSD can be used to approach newly diagnosed Type 1 and 2 patients and Type 2 patients with perceived difficulties.

The recommendations for further research are that it would be useful to develop and test a GSD programme for adolescents who are going to be transferred to clinics for adults, to disseminate studies of GSD, to conduct organisational studies of changes in diabetes teams as a consequence of introducing GSD and studies of shared care between diabetes clinics and general practitioners based on GSD of patients with difficulties in living with Type 1 or Type 2 diabetes.
Kapitel 13

Dansk resumé
Generel introduktion


Kapitel 1 introducerer ideen om at nuværende metoder i relationel problemløsning modarbejder implementering af empowerment i klinisk praksis og forhindrer patienters egenbeslutning i vanskelig diabetesomsorg. I dette kapitel bliver Guidet Egen-Beslutning placeret i en teoretisk helhed med empowerment som filosofi og udvikling af life skills (’livsdygtighed’ på dansk) med diabetes som mål for individuel patient omsorg. Livsdygtighed defineres som ”De personlige, sociale, kognitive og fysiske færdigheder der sætter mennesker i stand til at kontrollere deres liv og give det retning, samt udvikle kapacitet til at leve med og producere forandring i deres omgivelser.” Kapitlet omfatter desuden en kort præsentation af den begrebslige udvikling af life skills og argumenter for begrebet berettigelse i diabetesomsorg. Endelig gives der indblik i GEB’s brug af Lex Bos’ ‘metode til dynamisk udvikling af dømmekraft’ og Prochaska’s ’stages of change teori’.

Kapitel 1 præsenterer den overordnede hypotese, formål og mål med studiet:

Hypotese: Effektiviteten af relationel problemløsning til udvikling af patienters egenbeslutning i vanskelig diabetes omsorg vil øges hvis nuværende metoder bliver erstattet af metoder man ved er konsistente med empowerment og som er rustet til at overkomme barrierer i vanskelig diabetesomsorg.

Formål: At udvikle og teste en metode til relationel problem løsning som er konsistent med empowerment og rustet til at overkomme barrierer imod udvikling af livsdygtighed i vanskelig diabetes omsorg.
Målet med denne afhandling var:

1. At præsentere ‘groundede’ teorier udledt fra interaktion mellem patient og sundhedspersonale i vanskelig diabetes omsorg.
2. At præsentere Guidet Egen-Beslutning i detaljer og beskrive den deltagerbaserede forskningsproces der førte til udvikling af metoden.
3. At illustrere hvordan effekten af Guidet Egen-Beslutning blev evalueret kvalitativt i vanskelig diabetes omsorg.
4. At præsentere effekten af Guidet Egen-Beslutning på livsdygtighed med diabetes inkluderende den glykæmiske kontrol.
5. At diskutere resultaterne og deres konsekvenser for klinisk praksis og fremtidig forskning.

Kapitel 2 beskriver forskningsdesignet, der blev indledt med et grounded theory studie af interaktionen mellem patient og professionel i elleve relationer i forhold til problemer relateret til dårligt reguleret diabetes.

Tre 'groundede' teorier præsenterer fortolkning af barrierer i den relationelle problemløsning imod effektivt at fremme patienters egenbesluttede handlekompetence i diabetesomsorgen. Kapitel 3-5.
Kapitel 3 udviklede en teori om en prioriteringskonflikt mellem liv og sygdom.

At holde liv og sygdom adskilt blev identificeret som en kernekategori med tilknyttede konfliktlinier imellem og internt i patienter og sundhedsprofessionelle. Overordnet og upåagtet syntes denne konflikt at reducere udnyttelsen af de to parters kompetence i problemløsning. Tre tilgange til problemløsning påvirkede konflikten forskelligt: en hyppigst set kompliance-forventende tilgang fastholdt konflikten uforandret, en fiasko-forventende tilgang fik konflikten til at gå i hårdknude og en gensidigheds-forventende tilgang neutraliserede konflikten ved at parterne blev opmærksomme på hinandens særopfattelser på situationsniveau og derved effektivt kunne mobilisere deres handlekompetence.

Kapitel 4 udviklede en teori om Relationsbetinget forandringspotentiale

Kapitel 5 præsenterede *en person-specifik refleksionsmodel*.

Refleksionsmodellen er en idealtypisk model der viser mulige valg i en personspecifik refleksion. Den består af et horisontalt kontinuum forløbende fra en rent sygdomsorienteret tilgang til en rent livsorienteret tilgang krydset af et vertikalt kontinuum forløbende fra en situationsuafhængig refleksion til en situationsafhængig refleksion. De to linier krydser hinanden i hinandens balancepunkt hvor der placeret et fokus (zone 5), der omfatter det, som patienten aktuelt har svært ved at håndtere i livet med diabetes. Der skelnes mellem focuseringszone 1-5 og situationel refleksion dybde 0-IV. Gensidig refleksion viste sig at kræve zone-5 kommunikation og niveau III-IV i situationsbetinget refleksion, hvilket sjældent fandt sted.

Fundene fra disse tre grounded theory studier gav anledning til udvikling og implementering af Guidet Egen-Beslutning (GEB).

Kapitel 6 præsenterer en beskrivelse af GEB’s udvikling og implementering via deltagerbaseret forskning for at sikre accept og anvendelighed af GEB i en travl klinisk praksis. Sammenhængen mellem grounded theory fundene og udviklingen af specifikke arbejdspapirer beskrives i detaljer (Tabel 6.1. side 96-101) ligesom grundene til at avanceret professionel kommunikation var nødvendig. Der beskrives et kvalitativt interventionssstudie hvor GEB i stedet for traditionelle metoder blev anvendt til løsning af problemer relateret til vedvarende dårligt regul jeret Type 1 diabetes i 11 sygeplejerske-patient relationer. Den kliniske signifikans af GEB illustreres og diskuteres med hensyn til dens mulighed for at forandre de vanskelige mønstre der blev afdækket af de ’groundede’ teorier. GEB gjorde det lettere og hurtigere at skabe en person-specifik viden om vanskeligheder levet med diabetes i fællesskab hvilket demonstrerede en forløsende effekt i fire stadier: forløsende viden i bevidstheden, i en støttende relation, i teamet og i dagligdagen. Når patientspecifik viden bevægede sig gennem disse stadier blev en tendens til at holde liv og sygdom adskilt transformeret over i en tendens til at bygge bro mellem liv og sygdom.

Kapitel 7 præsenterer resultaterne af en randomiseret kontrolleret undersøgelse af effekten af GEB i et 16-timers gruppetræningsprogram (GEB-GT) for mennesker med vedvarende dårligt regulere d Type 1 diabetes. Voksne mellem 18 og 49 år blev inkluderet, med HbA1c gennemsnitligt $\geq 8.0\%$ i de sidste to år, sygdomsdebut $\leq 40$ år og insulínbehandling fra debuten. Deltagerne blev randomiseret i forholdet 3 til 2 til GEB-GT straks i 2001 (interventionsgruppe) eller forsinket
gruppetræning et år senere (kontrolgruppe). 50 patients (30 GEB-GT og 20 kontrolpatienter) fuldførte studiet. GEB-GT patienter opnåede bedre livsdygtighed med diabetes end kontrolpatienterne udtrykt ved a) øget støtte til autonomi fra sundhedsprofessionelle målt af Health Care Climate Questionnaire (p<0.01); b) øget antal selv-monitorerede blodsukre (p<0.001); c) øget selvoplevelset kompetence målt af Perceived Competence in Diabetes (p<0.01); d) færre diabetes-relaterede problemer målt af Problem Areas In Diabetes (p<0.05); og e) forbedret glykæmisk kontrol over 1 år målt ved A1C (p<0.01). Kapitel 6 konkluderer at patienter med vedvarende dårligt reguleret diabetes oplevede forbedring af livsdygtigheden med type 1 diabetes og A1C et år efter at have anvendt GEB i et gruppeteringsprogram. GEB bedømmes til at være en værdig kandidat til videre udvikling og udbredelse.

**Generel diskussion, konklusion og perspektiver**

Kapitel 8 diskuterer designet og metoderne anvendt i de forrige kapitler. Det anvendte design kan betegnes som programmatisk kvalitativ forskning afsluttet med teoribaseret randomiseret kontrolleret studie. Kapitlet diskuterer fordelene ved at basere en intervention på kvalitative fund som vej til at sikre at indholdet i en intervention passer til deltagernes behov, forbedrer mulighederne for at fortolke resultaterne og forøger anvendeligheden af resultaterne. Endelig beskrives svagheder og begrænsninger ved studiet.

Kapitel 9 diskuterer resultaterne af studiet og fremhæver at der kvalitativt kunne påvises et mønsterbrud i relationel problemløsning ved anvendelse af GEB idet patienternes tid før og mellem samtaler blev brugt konstruktivt og ideen 'compliance' viste sig at være en illusion når dannelse af personspecifik viden blev skabt. Det blev også konstateret at dette mønsterbrud kunne genfindes i gruppeforløb i et omfang der kunne indfanges af kvantitative metoder et år efter deltagelse i et 16 timers kursus. GSD placeres som led i en ny generation af metoder der i de seneste år har været under udvikling og menes anvendelige i egenbeslutet adfærdsforandring.

Kapitel 10 præsenterer konklusionerne at GEB har vist sig at være acceptabel og anvendelig af patienter og professionelle såvel i individuel som i gruppebaseret træning og at både kvalitative og kvantitative studier har kunnet dokumentere effekt af GEB i effektiv udnyttelse af patienters og professionelles kompetence i relationel problemløsning.
Kapitel 11 sætter studiets resultaterne i perspektiv og peger på de essentielle implikationer for praksis og for forskning. Udvalgte dele af GEB anbefales i standardplejen til alle type 1 and 2 patienter.

GEB i dens nuværerende version foreslås til type 1 diabetes patienter der oplever vanskeligheder i livet med diabetes uanset regulering, medens nye versioner af GEB kan tilpasses nydiagnostiserede Type 1 og 2 patienter og Type 2 patienter med oplevede vanskeligheder.

Som led i fortsat forskning blev det foreslået at udvikle og teste et GEB program for unge som skal overgå fra børneafdeling til ambulatorium for voksne. Studier til procesevaluering af tværfaglig implementering blev anbefalet for at undersøge effekten og accepten af GEB brugt tværfagligt. Det blev endelig foreslået at udforske GEB’s brugbarhed som led i ’shared care’ mellem diabetesklinikker og praktiserende lærer.
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Appendix A
Problem interpretation in grounded theory study 1996-1997

11 patients
8 nurses

Dyad A1 – A11

Development of Guided Self-Determination (GSD) 1998-2000

25 patients tried out parts of GSD*
12 nurses participated in implementation of and qualified in using GSD

6 nurses
6 changed job
moved

2 nurses

Qualitative intervention study testing the clinical significance of GSD in one-to-one setting 2000-2002

11 patients*
6 nurses

Dyad B1-B11

1 migrated 1 day & night unit

2 nurses

Randomised controlled trial (RCT) testing GSD in group-setting 2001-2003

30 completed GSD in group setting
6 nurses and 1 researcher

3 groups

20 completed as control patients receiving traditional care

1 patient
(from dyad A10)

2 nurses

2 patients
(from dyad A1 and A3)
Figure A 2. Flow of participants through the stages of guided self-determination programme, Aarhus University Hospital, Denmark 2001-2003.

Assessed for eligibility
713 Type 1 diabetes patients, 18-49 years old, had attended the clinics in the year 2000; 397 (56%) of whom had been living with an average HbA1c above 8.0% for two years according to the hospital laboratory.

Excluded (n = 336)
Not meeting inclusion criteria (n = 155)
Not responding to invitation (n = 97)
Refusing to participate in group training (n = 68)
Accepted participation in group training, but did not show up at randomisation (n = 16)

Randomized (n = 61)
balanced 3 to 2

Allocated to life skills group training 2001 (n = 36)
Received intervention (n = 33)
Did not receive intervention (n = 3)
One prevented due to job change, one due to divorce and one due to reluctance to participate in group setting

Allocated to control group and delayed training (n = 25)
One was excluded due to pregnancy (n = 1)

Lost to follow-up
Only attended 1 or 2 group sessions due to own or family disease (n = 2)
Did not return questionnaire at follow-up (n = 1)

Lost to follow-up
Have migrated (n = 2)
Did not return questionnaire at follow-up (n = 2)

Analysed (n = 30)
Analysed (n = 20)
Table A.1.  
Reasons why 155 patients with HbA1c values averaged ≥ 8.0% 1999-2000 did not meet the inclusion criteria and were therefore not invited.

<table>
<thead>
<tr>
<th>Reasons</th>
<th>No.</th>
<th></th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deceased</td>
<td>5</td>
<td>Mental reasons</td>
<td>9</td>
</tr>
<tr>
<td>Criteria for type 1 not fulfilled</td>
<td>10</td>
<td>Psychiatric reasons</td>
<td>8</td>
</tr>
<tr>
<td>Duration of disease &lt; 2 years</td>
<td>30</td>
<td>Language</td>
<td>8</td>
</tr>
<tr>
<td>HbA1c values missing</td>
<td>23</td>
<td>Pregnancy</td>
<td>7</td>
</tr>
<tr>
<td>Participated in implementation</td>
<td>13</td>
<td>Complications</td>
<td>8</td>
</tr>
<tr>
<td>Participated in qualitative intervention study</td>
<td>6</td>
<td>Distance from the clinics</td>
<td>4</td>
</tr>
<tr>
<td>Not longer attending clinics</td>
<td>19</td>
<td>HbA1c &lt; 8.0% at invitation</td>
<td>5</td>
</tr>
</tbody>
</table>

Table A.2.  
Reasons for non-participation stated by 68 patients who had returned questionnaires at baseline and refused to participate in GSD-GT. (It was allowed to mention more reasons)

<table>
<thead>
<tr>
<th>Reasons</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>I cannot find time for the course in the relevant period</td>
<td>31</td>
<td>46</td>
</tr>
<tr>
<td>I do not want to dedicate so much time for my diabetes</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>I am unable to participate at the dates and time stipulated</td>
<td>13</td>
<td>19</td>
</tr>
<tr>
<td>I am satisfied with my situation and have no desire to make any changes</td>
<td>11</td>
<td>16</td>
</tr>
<tr>
<td>I do not want to form part of a group, but would have accepted an individual course</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I do not believe that I would benefit from such a course</td>
<td>6</td>
<td>9</td>
</tr>
</tbody>
</table>

**Other reasons:**

- Pregnancy: 6 (9%)
- Distance to centre too long: 3 (4%)
- Have been participating in other trials: 4 (6%)


Appendix B
Patient Interview Guide Used at Discharge.

1. Admission
   Reasons/opinion  circumstances
   concerns
   doubts/questions
   what does the patient need assistance for?
   expectations

2. Living with diabetes
   Onset – what is still remembered about?
   - family’s reactions
   - friends’ reactions
   - colleagues’ reactions
   - own reactions
   Living conditions
   Values
   What has changed?
   Patient’s perception of own strong and weak points

3. Assignment
   What did you discover you needed assistance with at the admission interview?
   To what extent did the admission interview provide an overview of what you needed to do during the admission?
   How did you influence the decisions made?
   Did you decide to leave anything undone?

4. Thoughts and feelings exchanged with the nurse
   Do you know how the nurse perceives your situation?
   Does the nurse know how you perceive your situation?
   Do you view some aspects of your situation differently from the nurse?
   How do you feel about not agreeing with the nurse?
   What do you do when you disagree with her?
   In your opinion, are some aspects difficult to discuss with the nurse?
   Do you know the reasons for what has happened during your admission?

5. Benefit from cross-disciplinary/collegiate discussions
   How might you benefit from the team around you (nurse, dietician, doctor, chiropodist)?

6. Effect
   What have you received assistance with during the admission?
   How does this correspond to your expectations/hopes?
How would you evaluate the result of the admission?
In your opinion, what has been the most effective aspect of the admission?
Which part(s) have been less successful?
Is there anything you did not get assistance with? Who might help you with this?

7. Time use
How do you find your time has been put to use during admission?
Could your time have been spent more efficiently?
Has the staff dedicated the time needed to you?

8. Future
What are your thoughts on the future?
What is it important to preserve?
What would you like to change?
Do you have any worries?
Have you talked to the nurse about it?
Would you like to?

9. Final comment?
Is there anything you would like to add before ending the interview?
Appendix B.

Nurse Interview Guide Used at Discharge.

1. Patient’s reaction to diabetes
   Please tell me about your patient and how you find he/she is coping with the diabetes?

   How do you believe the disease affects him/her - Are there any particularly difficult aspects?

   Would you like him/her to do anything differently?
   - are any possibilities left untried by the patient?
   - have you observed any change in these areas during this admission?

   Has anything surprised you about the patient's reaction?
   - what may have caused the reaction?
   - have you discussed this with your patient?

   What do you believe to be the patient’s strong points?

   How have you reached this conclusion? Are there any points you are unsure about?

2. How did you discover that the patient needed help during this admission?
   - How was it decided?
   - Who took part in the decision process?
   - What was the motivation for the decision?

   Did the patient take part in deciding what you would focus on?
   - What, in your opinion, are the advantages and disadvantages of letting the patient take part in the decision process?
   - Which knowledge and experiences has the patient been able to contribute with?
   - In which situations did you discover this?
   - How would you describe the patient’s attitude to being involved in the process?

   How have you been able to benefit from your professional knowledge when nursing the patient?
   - Which knowledge do you believe the patient needed?
   - Is the patient aware of your knowledge?

3. How do you feel about having to assist the patient?
   - Have you, in any way, been surprised by your own reaction?
   - What may have caused this reaction?
   - Have you experienced anything during your interaction with the patient which you did not feel you could bring up in conversation with him/her?
   - What might have happened if you had brought it up?
   - Who do you turn to instead?

   How do you believe the patient feels about being a patient?
   - Why do you believe this is the case?

   Have you been particularly interested in, or preoccupied with, anything related to this patient?
   - Does your patient know?
Has anything annoyed you in relation to this patient?
- Could this have been avoided in any way?
- Do you know if the patient is aware of this?
- Why do you believe this to be the case?
Interview Guide 6 Months after Discharge (patients)

1. **When recalling the admission, what comes to mind?**
   a. What is your most positive recollection? What is your most negative recollection?
   b. Has the admission changed your opportunities?

2. **What has changed in your everyday life since the last time?**
   a. In relation to the diabetes, living with the disease – and regulation?
   b. In relation to other parts of your life?
      - Does anything feel different?
      - Do you do anything differently?
      - Has your attitude changed in any way?

3. **Are you satisfied with your everyday life now?**
   - Well-being?
   - Do you succeed where it is most important for you to do so?
   - Have any of the things you hoped for come true?

4. **What would you like to change?**
   - In which way?
   - Do you expect this to happen?
   - If so, when?
   - What if things do not change?

5. **Has your perception of hospital staff changed?**
   - Their support?
   - Your way of interacting with them?
   - Your interaction?

6. **Is there anything about living with diabetes that you find to be difficult?**
   - Have you been offered any assistance to deal with this during admission?
   - For which aspects do you still need help?
Appendix C
Proof of Competence

In the Use of Guided Self-determination

A Method for Strengthening the Life Skills of Diabetics

Participant XX

has acquired the relevant competence by participating in method development as described below under the guidance of Vibeke Zoffmann, RN, MPH, PhD student.

Aarhus University Hospital 1997 - 2003

Part 1.
The philosophical, theoretical and empirical background of the guided self-determination method (seven 60-minute lectures).

The course bibliography included the following authors:


Part 2.
Training in the use of method in clinical practice and participation in group and individual supervision with a view to testing and optimising the work sheets supporting guided self-determination.

Part 3.
Communication training:

• Mirroring
• Active listening
• Values clarification
• I-You sorted communication

Part 4.

Part 5.

Aarhus, February 2003.
Course programme

Lecture 1: Why use method in clinical health work?

1. What is a method? What does it mean to use method in clinical health work?
   • Any approach should be tailored to the people, assignments and barriers warranting its existence!

2. A person diagnosed with diabetes needs two types of professional assistance:
   • Medication and information concerning the disease and expedient disease behaviour.
   • Guidance to react optimally to limitations imposed by the disease on possibilities to realise values of life.
   • Consequently, there is a need for an approach capable of discovering the patient’s need and potential for change.

3. Why should the method be multidisciplinary? And what distinguishes method from the diagnosis and nursing care processes?
   • Patient’s awareness is the end. The professional’s’ awareness the means?
   • Is the patient’s knowledge and perspective attributed more significance?
   • Feelings experienced commonly by the two parties – positive as well as negative – are considered in order to benefit from their information value and avoid the risk of emotional blocking.
   • The applied problem solving model is dynamic, not linear.
   • The aim is multidisciplinary rather than monodisciplinary problem solving.

4. What about the time aspect?
   • What is efficiency and how may we employ our time more efficiently?
   • The patients’ time is considered a resource.

Lecture 2: Paradigm shift: from compliance to integration.

1. Strengthening of the patient’s resolve and consequently his/hers sense of responsibility.
   • I – You – sorting. What is it? – and why is it necessary?
   • Resolve is linked to the patient’s values, identity and integrity, his/her choices in the past, present and future, and confidence in own ability to succeed.
   • Why is it necessary to maintain a level of tension between patient and professionals’ in order to motivate for change?
2. The well-prepared patient who acknowledges himself/herself, is aware of the current situation and the choices it imposes on him/her.
   • Patient's version of past life with diabetes.
   • Patient’s version of current problems.
   • Patient’s version of own reactions to risk exposure.
   • Patient’s version of risk factors in current situation.

3. How diabetes can affect a person’s identity and integrity - and the significance of being given the opportunity to "tell your story".

_____________

**Lecture 3: The system’s knowledge in the future: general disease-specific knowledge combined with person-specific knowledge?**

1. How to proceed from a situation in which reality dictates a narrow medical point of view and the unattainable ideal for nurses is a holistic approach?
   • What is the difference between information and knowledge?
   • Generalised knowledge – advantages and limitations.
   • Specific knowledge about persons and situations.
   • Hardening of "soft data". From jelly fish to manageable problem.
   • Labelling the problem in a way which is satisfactory to both parties.

2. Creating a framework: Focussing on aspects which the professional and the patient consider particularly difficult to handle for the patient.
   • Agreeing on what the framework may include.
   • Agreeing to delimit a specific, manageable aspect to ensure that the work done during admission focus on that which the professionals and the patient believe the patient would benefit most from.

3. Focusing – the process in which the patient and the professional look for focal points which may lead to problem identification.
   Deliberate invitation to focus and invitation to de-focus.

4. Problem list - providing an overview of and denomination for current problems as identified by the professionals and by the patient.

5. Cooperation agreement – selected problems are agreed upon as the objective for the cooperation during admission and the period immediately following admission.

_____________

**Lecture 4: Patient’s attitude as object of investigation and intervention.**

1. Crossing perspectives – you choose!
• You may interchange the 2 focus areas a) symptoms and b) patient reactions
• Where patient reactions are identified as the centre of attention this also constitutes a turning point and an opportunity for concrete or abstract reflection.

2. The concept of attitude explains why there is not always a simple relationship between the patient’s attitude - and therefore preparedness to act – and the patient’s knowledge and values. Attitude may be divided into 4 dimensions and an internal discussion or tug-of-war between these 4 dimensions continuously takes place, causing various needs to be channelled:

• To perceive the world and act according to your own knowledge, creating a meaningful and coherent understanding of life.
• To live your life in accordance with your own recognised values.
• To perceive the world and live your life in a way that shields your ego.
• To perceive the world and life adapting to the surrounding world.

3. Types of reactions to risk:
• Reactions to the disease.
• Reactions to the behaviour of professionals.

Lecture 5: Having to deal with professionals throughout the course of life – how to avoid creating animosity and problems? – how to break inappropriate patterns?

1. Types of relations – patterns we are unaware of and which create a positive or negative inertia in our preparedness to act.

2. Resistance – distinguishing between different types. Capacity to endure resistance.


4. From “about communication” to “with communication”.

5. Preparation through conversation with colleagues.

Lecture 6: The meaningful conversation as a means of ensuring that time and effort are not wasted on relational problems. Returning focus to the patient’s problems. Realising potential for change.
I-You-sorted communication leads to honesty and generates meaning. Unsubstantiated hypotheses are replaced by knowledge, and misunderstandings are avoided.


2. Responding to increased value awareness.

3. Patient exercises for reflection and decision making.
   • "Less of…"
   • "More of …"
   • "Advantages and drawbacks"
   • "Unfinished sentences"
   • "What impedes…?"
   • "The time perspective opener"
   • "Risks and opportunities"
   • "The alliance-free group conversation"

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Lecture 7. Conclusion: facilitating the continuation of the person-centred approach.

1. Securing and storing person-specific knowledge in the system.

2. Maintaining cooperative relations.

3. Maintaining and fulfilling cooperation agreements.
Appendix D
## Work sheets filled out ✓ and discussed 

### 1. Agreement to work together

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>1a. Invitation to work together *</td>
<td>Problem lists</td>
<td></td>
</tr>
<tr>
<td>1b. Progression form *</td>
<td>Problems currently being worked on</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Agreement on follow-up</td>
<td></td>
</tr>
</tbody>
</table>

### 2. Your life with diabetes

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2a. Important events and periods in your life *</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2b. What do you find difficult at present living with your diabetes? *</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2c. Unfinished sentences: needs, values, experiences and opportunities*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2d. A picture, metaphor, or expression describing your life with diabetes*</td>
<td></td>
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<tr>
<td>2e. Room for diabetes in your life? *</td>
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</tbody>
</table>

### 3. Between ideal and reality

<p>| | | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>3a. Your experiences with recommended ways of living *</td>
<td></td>
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</tr>
<tr>
<td>3b. Your plans for changing your way of life *</td>
<td></td>
<td></td>
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<tr>
<td>3c. Own experiences with different types of treatment *</td>
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<td></td>
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<tr>
<td>3d. Your ideal goals for daily blood glucoses *</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3e. Blood glucoses, as you know them from experience *</td>
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<tr>
<td>3f. Advantages and disadvantages of high and low blood sugar *</td>
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<tr>
<td>3g. Blood sugar checks and your reasons for checking *</td>
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### 4. Working to change

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<thead>
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<tbody>
<tr>
<td>4a. Current problem solving *</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4b. Dynamic problem solving *</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4c. Pros and cons</td>
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<tr>
<td>4d. More of</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4e. Less of</td>
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</tr>
<tr>
<td>4f. Mannina behaviour</td>
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</tbody>
</table>
Invitation to work together in groups
Life skills with type 1 diabetes

What should be the focus of our cooperation?
- Whatever you currently find difficult in daily life with diabetes. Aspects which you will be able to shed light on and possibly change by drawing on your personal resources and those of the other group participants

What are our roles?
- You should regard yourself as the final decision-maker in matters concerning your situation, but feel free to make use of ideas and suggestions from group participants and course leaders
- Both your own and your collaborators’ knowledge and experience is needed
- Together we will aim at spending our time in the best possible way on matters that we consider important
- Part of the time we will be working in small groups, at other times we will gather to discuss important points together

How should we work together?
- It is OK for you and others to perceive your situation differently
- It is necessary that we know each other’s opinion
- Disagreeing is OK
- Having and showing emotions is OK
- Pressing others or letting others press yourself to change opinion is not OK

We will use work sheets - what are the advantages of this method?
- You can use them for reflection and for gaining insight into your situation – in peace and quiet
- We can use them for gaining a general understanding of what is important in your situation
- They make it easier to talk about the more difficult aspects of diabetes
- They help you making decisions tailored to your needs. Decisions which will therefore make sense after the course
- They help us to stay on course
- Finally, they are useful for keeping track of our agreement and the goals you have defined for the future

Best wishes from the course leaders
Progressing in life with diabetes (Individual programme)

**Invitation to cooperate**

What should our cooperation focus on?
- We will choose aspects which are currently causing you problems in your daily life with diabetes

What will be your role and mine?
- We need to draw on the experience and knowledge of both of us
- We will both be active and make the most of our time by focusing on aspects we consider important
- Sometimes we will work individually and at other times we will work together

What should characterise our cooperation?
- It is OK if you and I perceive your situation differently
- Disagreeing is OK
- Having and showing emotions is OK
- It is necessary to know each other’s points of view

We will use work sheets - but what are the advantages of using work sheets?
- You can use them for reflection and for gaining insight into your situation – in peace and quiet
- We can use them for gaining a general understanding of what is important in your situation
- They make it easier to talk about the more difficult aspects of diabetes
- They help you making decisions tailored to your needs. Decisions which therefore make sense after the course
- They help us to stay on course

Best wishes from your contact nurse
### Progression paper

<table>
<thead>
<tr>
<th>Admitted from:</th>
<th>to:</th>
<th>(patient label)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Primary team: physician(s):</th>
<th>nurse:</th>
<th>dietician:</th>
<th>others:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient’s list of problems:</th>
<th>Professional’s list of problems:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Problems selected for guided self-determination:</th>
<th>What the patient wants to change later:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Final agreement:</th>
<th>will, for the date:</th>
<th>200</th>
<th>aim for:</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
</tbody>
</table>

1. ____________________________________________

2. ____________________________________________

3. ____________________________________________

4. HbA1c at: _____ (HbA1c x 2) – 6, equivalent to an average blood glucose of: _____

<table>
<thead>
<tr>
<th>Patient’s effort</th>
<th>Professional and other support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Outpatient visit. / 200_  Physician: _______ Nurse: _______ Dietician: _______

What has been accomplished? ______________________________________________________

__________________________________________________________

__________ will, by the date ______ year 200_ aim for:

1. __________________________________________________________

2. __________________________________________________________

3. __________________________________________________________

4. HbA1c at: ______ (HbA1c x 2) – 6, equivalent to an average blood glucose of: ______

Patient’s effort: ___________________________ Professional and other support: ______________

__________________________________________________________

__________________________________________________________

Outpatient visit. / 200_ Physician: _______ Nurse: _______ Dietician: _______

What has been accomplished? ______________________________________________________

__________________________________________________________

__________ will, for the date ______ 200_ aim for:

1. __________________________________________________________

2. __________________________________________________________

3. __________________________________________________________

4. HbA1c at: ______ (HbA1c x 2) – 6, equivalent to an average blood glucose of: ______

Patient’s effort: ___________________________ Professional and other support: ______________

__________________________________________________________
Important events and periods in your life with diabetes

State the year you were diagnosed with diabetes
Indicate the start and endpoints of longer periods in which your diabetes was well regulated
(mark with a W or draw a thick line on the timeline above) W

Indicate the start and endpoints of longer periods in which your blood glucose was high
(mark with an H on the line or draw a line above the timeline) H

Indicate the start and endpoints of longer periods in which you have experienced many low blood glucoses
(mark with an L on the line or draw a wavy line under the timeline) L

Indicate the start and endpoints of a longer period in which you have experienced fluctuating blood glucoses
(mark with an F or draw a wavy line on the timeline) F

Indicate the reasons you believe explain periods with good or poor regulation (write catchwords)
Indicate important events or experiences that you believe to have had a positive or negative effect (write catchwords)
Indicate conditions of living- and/or working that you believe have been decisive (write catchwords)

Example - see reverse!
Example of “Important events and periods in your life with diabetes”

1973 born
1985 12 years old diagnosed with diabetes
1989 16 years old Moved to Aarhus from Vejle
1993 20 years old
2000 27 years old

W H W H / F
moved to Århus from Vejle
Insulin pen four times insulin.
Worked in garden centre
Apprentice in an office.
My mother died
Moved in with my boyfriend
What do you currently find difficult about living with your diabetes?

Write some catchwords:

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________
Unfinished sentences – needs, values, experiences and opportunities

Those who know how I live, think that I……

The happiest day in my life was when……

The saddest day of my life was when……

Regarding my diabetes, I am best at ......

The worst thing about having diabetes is......

I am not good at......

My diabetes has prevented me from......

It will not prevent me from......

In a years time I will......

I should not blame my diabetes for......

When I am due at the outpatient clinic, I think of ......

I would like to learn more about......

Things that can give problems at home......
I think that my colleagues/friends.....

Things I try to change about myself.....

A habit I find it difficult to change is.....

I find it difficult to resist pressure from.......

I get good support from......

I get no support from......

In spite of having diabetes I can......

What I most of all wish for is ......

When I am at the end of my life, I would like to look back on having .......
Appendix D.2.d

A picture, metaphor or expression describing your life with diabetes

Which picture do you associate with having to live with diabetes?

Label:
Room for diabetes in your life.

My diabetes has taken up so much room up to now

(mark the area)

My diabetes will take up so much room in the future

(mark the area)

What is the difference?
Your experiences with recommended rules for life

Many of the rules recommended to people with diabetes are difficult to fit into everyday life. How do you fit the following rules into your life?

Fill in an X on every line.

<table>
<thead>
<tr>
<th>My everyday life is characterised by the fact that I:</th>
<th>I have done this regularly for...</th>
<th>No - I have tried, but without success</th>
<th>No - I have not tried</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>more than 5 years</td>
<td>more than 6 months and less than 5 years</td>
<td>less than 6 months</td>
</tr>
<tr>
<td>..eat 3 snacks a day in between meals</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>..only eat and drink the recommended amount of sugar</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>..only eat what I need when my blood glucose is low</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>..only eat the recommended amount of fat</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>..exercise as recommended</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>..always take the insulin that I need</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>..adjust the insulin or food intake according to need</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>..lose the necessary weight</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>..have stopped smoking</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>..have reduced my use of tobacco</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>..avoid problems with alcohol</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>..make sure to discover low blood glucose in time</td>
<td></td>
<td></td>
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<tr>
<td>..check my blood or urine as recommended</td>
<td></td>
<td></td>
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<tr>
<td>..avoid harmful stress</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>..take other subscribed medication regularly</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Mark if the following statements apply to you:
Weight loss is not relevant for me as I have not been overweight □
Smoking is not relevant for me as I do not smoke □
I do not take any other medication than insulin □
Your plans to change your way of life

Mark sentences describing your everyday life with an X in the left-hand column. Indicate whether you would like to change behaviour in the right-hand columns (also with an X)

<table>
<thead>
<tr>
<th>Characteristics of my everyday life:</th>
<th>I will like to change (put X) within the first month</th>
<th>I will like to change (put X) within the first 6 months</th>
<th>I will like to change (put X) after the first 6 months</th>
<th>I have no plans for changing my behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>I skip snacks between meals</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I eat and drink larger amounts of sugar than recommended</td>
<td></td>
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<tr>
<td>I eat too much when my blood glucose is low</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I eat more fat than recommended</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I do not exercise enough</td>
<td></td>
<td></td>
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<tr>
<td>I some times do not take the amount of insulin I need</td>
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<tr>
<td>I do not adjust my intake of insulin and food according to need</td>
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<tr>
<td>I am overweight</td>
<td></td>
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<tr>
<td>I smoke</td>
<td></td>
<td></td>
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<tr>
<td>I have problems with alcohol</td>
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<tr>
<td>I discover low blood glucoses too late</td>
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<tr>
<td>I do not check my blood or urine as recommended</td>
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<tr>
<td>I am often under harmful stress</td>
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<tr>
<td>I some times do not take prescribed medication</td>
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<td>....</td>
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</table>

Total:
**Own experiences with different types of treatment**

<table>
<thead>
<tr>
<th>Type of treatment:</th>
<th>Period:</th>
<th>Advantages:</th>
<th>Disadvantages:</th>
</tr>
</thead>
<tbody>
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</table>

**Suggestions and ideas:**

[Blank space for additional comments]
Your ideal goals for daily blood glucoses

Research has shown that you can reduce the risk of long-term damage by keeping your blood glucose at a low level. The disadvantage is that you may experience more instances with too low blood glucose levels.

We feel that the long-term test, HbA1c, has been given a far too negative nick name “the tell tale” test. As the test can be used by diabetics to keep themselves on the right track, we suggest that the test be named the “Landmark Sample”.

Write down the highest and lowest blood glucose that YOU would be content with at the following times:

<table>
<thead>
<tr>
<th>Blood Glucose</th>
<th>Before Breakfast</th>
<th>1½ h After Breakfast</th>
<th>Before Lunch</th>
<th>1½ h After Lunch</th>
<th>Before Supper</th>
<th>1½ h After Supper</th>
<th>MIdnight</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Highest</td>
<td>AT</td>
<td>AT</td>
<td>AT</td>
<td>AT</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lowest</td>
<td>Breakfast</td>
<td>Lunch</td>
<td>Supper</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Overall average = \( \text{HbA1c} \)

<table>
<thead>
<tr>
<th>HbA1c</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average BS</td>
<td>4.5</td>
<td>6</td>
<td>8</td>
<td>10</td>
<td>12</td>
<td>14</td>
<td>17</td>
<td>19</td>
</tr>
</tbody>
</table>

Mmol/l
Blood glucoses as you know them from experience

What does reality say - and what do you know about it? Insert typical results from your measurements. Add a question mark if you do not know a value.

<table>
<thead>
<tr>
<th>BLOOD GLUCOSE</th>
<th>1½ h</th>
<th>1½ h</th>
<th>1½ h</th>
<th>A T TIME</th>
<th>M I D N I G H T</th>
<th>A V E R A G E</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breakfast</td>
<td>B R E A K F A S T</td>
<td>L U N C H</td>
<td>S U P P E R</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Highest</td>
<td>B R E A K F A S T</td>
<td>L U N C H</td>
<td>S U P P E R</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lowest</td>
<td>B R E A K F A S T</td>
<td>L U N C H</td>
<td>S U P P E R</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Conversion into HbA1c:

<table>
<thead>
<tr>
<th>HbA1c</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>4.5</td>
<td>6</td>
<td>8</td>
<td>10</td>
<td>12</td>
<td>14</td>
<td>17</td>
<td>19</td>
</tr>
<tr>
<td>BS Mmol/l</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total average ➔
## Advantages and disadvantages of blood sugar regulation

<table>
<thead>
<tr>
<th>HbA1c result before course:</th>
<th>%</th>
</tr>
</thead>
</table>

**HbA1c to be at the following points in time?**

<table>
<thead>
<tr>
<th>HbA1c</th>
<th>HbA1c</th>
<th>HbA1c</th>
<th>HbA1c</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goal</td>
<td>Goal</td>
<td>Goal</td>
<td>Goal</td>
</tr>
<tr>
<td>Result</td>
<td>Result</td>
<td>Result</td>
<td>Result</td>
</tr>
<tr>
<td>Date</td>
<td>Date</td>
<td>Date</td>
<td>Date</td>
</tr>
</tbody>
</table>

In which situations do you especially want to avoid low blood sugar?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Advantages and disadvantages of regulating high and low blood sugar

What do we actually know?

The New England Journal of Medicine

The higher the HbA1c, the greater is the known risk of developing lasting changes, for instance in the eyes. The lower the HbA1c, the greater the risk of serious situations with low blood sugar (for instance situations where you cannot do without the help of others)

Curves show how often this happens during 100 patient years:

i.e. for 100 persons during a 1-year period
or for 20 persons during of 5-year period
or for one person during a 100-year period
Measurements of blood glucoses and your reasons for measuring

<table>
<thead>
<tr>
<th>Date</th>
<th>Before Breakfast</th>
<th>1½ h</th>
<th>Before Lunch</th>
<th>1½ h</th>
<th>Before Dinner</th>
<th>1½ h</th>
<th>After Bedtime</th>
<th>Mid Night</th>
<th>After Breakfast</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Add one or more letter/s according to your reasons for measuring each blood glucose

- A - agreement
- L - detecting/preventing low blood glucose
- Hi - detecting high blood glucoses
- Y - for your sake
- M - for my sake
- C - curiosity
- P - profile
- H - habit forming

<table>
<thead>
<tr>
<th>HbA1c</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>4.5</td>
<td>6</td>
<td>8</td>
<td>10</td>
<td>12</td>
<td>14</td>
<td>17</td>
<td>19</td>
</tr>
<tr>
<td>BS</td>
<td>Mmol/l</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Patient label
Current problem-solving

Pick a name for what is causing you problems: ..............................................

Your observations

How long have you experienced this?

How often do you experience it?

Has it increased or decreased over time?

When do you notice the problem the most?

When do you notice the problem the least?
Your thoughts and feelings

What do you think the problem is related to?

<table>
<thead>
<tr>
<th>What makes it worse?</th>
<th>What makes it better?</th>
</tr>
</thead>
</table>

What does it stop you from doing?  What do you achieve by it?

How much does it affect you?
Your goals and intentions

What is important to you? - What are you aiming for?

What can you/other people gain by solving the problem?  
What can you/other people loose by solving the problem?  

In the short term?  
In the short term?  

In the long term?  
In the long term?  

Have you decided whether you want to solve the problem completely or partly?

If partly - which parts?
Your actions

Which partially successful attempts have you made in order to solve the problem?

<table>
<thead>
<tr>
<th>When?</th>
<th>Who helped you?</th>
<th>Who have you lacked help from?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How often?

Any unsuccessful attempts?

<table>
<thead>
<tr>
<th>Who have you asked for help?</th>
<th>Who would you like to have asked for help?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
“Pros and Cons” (Arborelius)

- Very good
- Good
- Not so good
- Bad

Label:
"More of"

I am standing here now

I am aiming to stand here by the .../...

This makes it easier

This makes it more difficult

I would like to reach this level

Source: Arborelius
“Less of”

I am standing here now

I am aiming to stand here by the ../..

I would like to reach this level

This makes it easier

This makes it more difficult

Source: Arborelius
What usually causes you to feel like this?

What unsuccessful attempts to change it have you made?

What usually happens when you feel like this?

An emotion/feeling that troubles you:

What problems does it usually cause?

What new things can you think of doing?

What would it be like if you could deal with it in a better way?

Legend

L: Leads to
C: Characterised by
Your observations

Not so many people know that I have DM. So I don’t get asked so many questions.

The problem has got bigger over time. Notice it most when I am together with people who know a bit about diabetes, ask questions and say, “You can’t do that”!

What causes problems:

- Get angry and irritable.
- Get embarrassed and angry about having diabetes.
- Get embarrassed and angry about not being able to give a proper explanation and so just say something without being certain about it.

Your thoughts and feelings

Don’t want to lie at work. It will rebound on me.

Summary

Future problem solving

Want to feel better about myself

Problem solving up to now

Have often (about twice a week) thought, “Tomorrow I’ll make a fresh start”.

What causes problems:

- Want to give the impression things are going better than they really are.

Your goals and intentions

Want to feel better about myself

Would like to avoid arguments.

Your actions

Want to tell the truth and say, “I don’t know”, if I don’t know.

Your actions

Don’t want to lie at work. It will rebound on me.

Want to feel better about myself.
Instances of new registered lasting changes in eyes* 

Serious instances of low blood sugar**

<table>
<thead>
<tr>
<th>HbA1c</th>
<th>10.5%</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 instances in 5 years for a group of 20</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HbA1c</th>
<th>7.0%</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 instances in 5 years for a group of 20</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HbA1c</th>
<th>5.5%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 instance in 5 years for a group of 20</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HbA1c</th>
<th>5.5%</th>
</tr>
</thead>
<tbody>
<tr>
<td>100 instances in 5 years for a group of 20</td>
<td></td>
</tr>
</tbody>
</table>

* A new deterioration which it has been possible to register in one eye for ½ year, measured as at least 3 steps on a so-called ETDRS-scale consisting of 25 steps

** Insulin events which cannot be managed without the help of others
One way of using HbA1c:

BG – BG – BG!

I perhaps passively accept the HbA1c target that the professionals recommend.

After that I let HbA1c be used to look back and discover, reveal or spill the beans about what my blood sugar level has been.

Depending on the outcome I can either feel like a good, obedient patient or like I have failed or been found out. At the same time I can feel that professionals are people who meet me with a wagging finger or give me a clip round the ear.

Another way of using HbA1c:

I set my own target for HbA1c, which I think will be good for me and that I will be able to achieve.

I then use that to look forwards - as a point I can aim for at my own speed.

I am curious about what my blood sugar level is because I want to know whether I am headed in the right direction.
Appendix E
## Scales and their corresponding number in questionnaires at baseline and 1 year follow-up

<table>
<thead>
<tr>
<th>Scales</th>
<th>Questionnaire May 2001 Baseline</th>
<th>Question number:</th>
<th>Questionnaire August 2002 1-year follow up</th>
<th>Question number:</th>
</tr>
</thead>
<tbody>
<tr>
<td>HCCQ (5 items)</td>
<td>26-30</td>
<td></td>
<td>During GSD group-training answered retrospectively 1 year after: 21-25</td>
<td></td>
</tr>
<tr>
<td>TSRQ</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autonomy subscale</td>
<td>32,34,38,41,44,47,49,50.</td>
<td></td>
<td>34,36,40,43,46,49,51,52.</td>
<td></td>
</tr>
<tr>
<td>Controlled subscale</td>
<td>31,35,36,37,39,40,42,45,48.</td>
<td></td>
<td>33,37,38,39,41,42,44,47,50.</td>
<td></td>
</tr>
<tr>
<td>Amotivation subscale</td>
<td>33,43,46,51.</td>
<td></td>
<td>35,45,48,53.</td>
<td></td>
</tr>
<tr>
<td>PCD (3 items)</td>
<td>52,54,56.</td>
<td></td>
<td>54,56,58.</td>
<td></td>
</tr>
<tr>
<td>PAID (20 items)</td>
<td>57-76.</td>
<td></td>
<td>59-78.</td>
<td></td>
</tr>
<tr>
<td>Emotional related</td>
<td>59,62,63,64,65,66,68,69,70,71,72,75,76.</td>
<td></td>
<td>61,64,65,66,67,68,70,71,72,74,77,78.</td>
<td></td>
</tr>
<tr>
<td>Treatment related</td>
<td>57,58,71.</td>
<td></td>
<td>59,60,73.</td>
<td></td>
</tr>
<tr>
<td>Food related</td>
<td>60,61,67.</td>
<td></td>
<td>62,69.</td>
<td></td>
</tr>
<tr>
<td>Social support related</td>
<td>73,74.</td>
<td></td>
<td>75,76.</td>
<td></td>
</tr>
</tbody>
</table>
Read this before completing the questionnaire

The questionnaire has several parts with different subject categories:

- Your insulin treatment
- Your visits to the outpatient clinic
- Managing your diabetes
- Problems related to diabetes

You should answer the questions in the sequence in which they are presented in the questionnaire and follow any instructions given (instructions appear in parenthesis).

It is essential,
- that you answer all the questions
- that you answer as honestly as possible
- that you answer the questions yourself

How to complete the questionnaire

Mark the circle corresponding to the answer of your choice. Make sure your marks fill the circles. Marks covering the original circle are accepted. Please use a black marker as the questionnaire is read mechanically.

Correct:  ●
Incorrect:  ❌

In some questions you will be instructed to write digits and letters. Please write as clearly as possible and try to make your writing resemble these examples:

1 2 3 4 5 6 7 8 9 0

If you make a mistake, simply add a minus sign by the incorrect marking and fill out the correct circle.

It is important that you answer all the questions. If you cannot find an option covering the answer you would prefer, simply select the one that seems to fit your opinion best.

For any further questions or comments, feel free to contact:

Vibeke Zoffmann Knudsen
Department of General Practice
Vennelyst Boulevard 6
8000 Århus C
E-mail: vzk@alm.au.dk

or by phone 8942 6042
Working days from 9am. to 3pm.

Thank you very much for your help!

Please start filling out the questionnaire here:

1. Please state your civil registration number

2. Are you a woman or man?
   ○ Woman   ○ Man

3. Form completion date:

4. How do you currently live?
   ○ I live with my spouse/partner
   ○ I live alone (not married/divorced/separated/widow or widower)

5. How tall are you?    cm

6. How much do you weigh?    kg
7. State your occupational status (only one option may be selected).

- Employed
  - Self-employed trader (or assisting spouse)
  - Public servant
  - Servant (private sector)
  - Skilled worker
  - Semi-skilled or unskilled worker
  - Apprentice/trainee

- Not employed
  - House wife
  - Old-age pensioner
  - Early disability pension
  - Early retirement allowance
  - Unemployed
  - Social security benefit
  - Student, pupil
  - Other, please specify: __________________________

8. State your occupation in your own words:
(Please specify: For example: owner-farmer instead of just farmer, journeyman smith instead of just smith, head of department with the taxing authorities instead of just head of department)

__________________________________________________________ S F I

9. Do you have any employees/subordinates?

- No
- Yes, how many? ______

10. Which schooling have you received?
(select one option only)

- I am currently attending basic school training
- 7 years of schooling or less
- 8-9 years of schooling
- 10 years of schooling
- High school graduate or equivalent (HF, HHX, HTX)
- Other (including foreign school): __________________________

11. Have you completed any vocational training?
(select one option only)

- Yes, as a semi-skilled worker
- Yes, the introductory year at a technical school or business college (EFG or HG)
- Yes, completed apprenticeship or training at technical school or business college (EFG or HG)
- Yes, other technical or professional training to become a skilled worker
- Yes, further education, less than 3 years duration
- Yes, further education, 3-4 years duration
- Yes, further education exceeding 4 years duration
- Yes, other training, specify which: __________________________
- No, I have not received any vocational training
12. How old were you, when you were diagnosed with diabetes? 

years

13. How long have you had diabetes? 

years

14. How often does your diabetes prevent you from doing your normal daily activities (could not work or go to school, or visit friends)? (circle one number)

Never 1 2 3 4 5 6 7 Frequently

15. How would you rate your understanding of diabetes and its treatment? (circle one number)

Poor 1 2 3 4 5 6 7 Excellent

16. Please circle the number that indicates how able you are to fit diabetes into your life in a positive manner? (circle one number)

Not at all able 1 2 3 4 5 6 7 Very able

17. How do you take your insulin?

○ I use a pen
○ I use a pump

18. Which insulin type(s) do you use?

<table>
<thead>
<tr>
<th>Insulin type</th>
<th>Fast acting</th>
<th>Slow acting</th>
<th>Mixed insulin</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>10:90</td>
<td>20:80</td>
<td>30:70</td>
</tr>
<tr>
<td></td>
<td>40:60</td>
<td>50:50</td>
<td></td>
</tr>
</tbody>
</table>

State your current insulin consumption on an average day

- Morning
- Midday
- Evening
- Bedtime
- Extra

Only if you use a pump

- Basal rate 

How often do you forget/refrain from taking your insulin?

○ Every day
○ One or more times a week
○ One or more times a month
○ Never or almost never
19. Do you measure your blood sugar?
   - Yes
   - No (If no, please proceed to question 24)

20. How many times have you measured your blood sugar during the last 7 days?
   - ___ times

21. How many times have you measured your blood sugar during the last month?
   - ___ times

22. How often do you adjust your insulin dose according to your measurements?
   - Every day
   - One or more times a week
   - One or more times a month
   - Never or almost never

23. Have you discussed the results of your home measurements with the health staff during your last visit at the outpatient clinic?
   - Yes
   - Nej
   - I do not remember

24. Have you received any training in adjusting your insulin dose according to your blood sugar measurements?
   - Yes
   - No
   - I do not know

25. Are you confident with adjusting your insulin dose?
   - Not confident at all
   - Not very confident
   - Fairly confident
   - Very confident

26. I feel that my health practitioners have provided me choices and options about handling my diabetes.

27. I feel understood by my health practitioners with respect to my diabetes.

28. My health practitioners convey confidence in my ability to make changes necessary to control my diabetes.

29. My health practitioners encourage me to ask questions about my diabetes.

30. My health practitioners try to understand how I see my diabetes before suggesting a new way to do things.
There are a variety of reasons why patients take their medications, check their glucoses, follow their diet, or exercise regularly. Please consider the following behaviors and indicate how much you agree or disagree with each reason using the scale provided.

A. I take my medications for diabetes and check my glucoses because:

<table>
<thead>
<tr>
<th>Reason</th>
<th>Strongly disagree</th>
<th>Moderately disagree</th>
<th>Slightly disagree</th>
<th>Neutral</th>
<th>Slightly agree</th>
<th>Moderately agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>31. Other people would be mad at me if I didn't.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. I find it a personal challenge to do so.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. I don't know why I'd try - I won't be successful.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>34. I personally believe that controlling my diabetes will improve my health.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35. I would feel guilty if I didn't do what my doctor said.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. I want my doctor to think I'm a good patient.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>37. I would feel bad about myself if I didn't.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38. It's exciting to try to keep my glucose in a healthy range.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>39. I don't want other people to be disappointed in me.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

B. The reason I follow my diet and exercise regularly is that:

<table>
<thead>
<tr>
<th>Reason</th>
<th>Strongly disagree</th>
<th>Moderately disagree</th>
<th>Slightly disagree</th>
<th>Neutral</th>
<th>Slightly agree</th>
<th>Moderately agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>40. Other people would be upset with me if I didn't.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>41. I personally believe that these are important in remaining healthy.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>42. I would be ashamed of myself if I didn't.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>43. It's easier to do what I'm told than to think about it.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>44. I've carefully thought about my diet and exercising and believe it's the right thing to do.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45. I want others to see that I can follow my diet and stay fit.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>46. I don't know why; I'd just do it because my doctor said to.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>47. I feel personally that watching my diet and exercising are the best things for me.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>48. I'd feel guilty if I didn't watch my diet and exercise.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>49. Exercising regularly and following my diet are choices I really want to make.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50. It's a challenge to learn how to live with diabetes.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>51. I'm not sure why I'd follow a diet or exercise, I'll wait and see.</td>
<td>○ ○ ○ ○ ○ ○ ○ ○</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Please read each item and mark the circle corresponding the number that indicates your level of agreement with that statement.

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Moderately disagree</th>
<th>Slightly disagree</th>
<th>Neutral</th>
<th>Slightly agree</th>
<th>Moderately agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>52. I feel confident in my ability to manage my diabetes.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>53. I now feel capable of handling my diabetes.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>54. I am able to do my own routine diabetic care now.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>55. I feel confident discussing my diabetes with my care provider.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>56. I am able to meet the challenge of controlling my diabetes.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

Which of the following diabetes issues are currently a problem for you? Mark the circle corresponding the number that gives the best answer for you. Please provide an answer for each question.

<table>
<thead>
<tr>
<th></th>
<th>Not a problem</th>
<th>Minor problem</th>
<th>Moderate problem</th>
<th>Somewhat serious problem</th>
<th>Severe problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>57. Not having clear and concrete goals for your diabetes care?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>58. Feeling discouraged with your diabetes treatment plan?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>59. Feeling scared when you think about living with diabetes?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>60. Uncomfortable social situations related to your diabetes care (e.g., people telling you what to eat)?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>61. Feelings of deprivation regarding food or meals?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>62. Feeling depressed when you think about living with diabetes?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Confirmation

I hereby confirm that, after having received information concerning the project "Progressing in Life with Diabetes", I am willing to participate in the outlined trial.

I would like to participate in the course and be invited to a briefing session.:  ○ Yes  ○ No

I will only be able to participate if the following requirement(s) is(are) fulfilled:  __________________________________________________________

If no, please answer the following questions:

○ I cannot find time for the course in the relevant period
○ I do not want to dedicate so much time to my diabetes
○ I am unable to participate at the dates and times stipulated
○ I am satisfied with my situation and have no desire to make any changes
○ I do not want to form part of a group, but would have accepted an individual course offer
○ I do not believe that I would benefit from such a course
○ Other reasons, please specify  __________________________________________________________
○ I am in doubt and would like to be contacted at phone no.:  __________________________________________________________

I have been informed that participation is voluntary and that at any point in time and without stating my reasons for doing so, I may change my decision to participate. I am also aware that leaving the trial will have no consequences for my current or future care or treatment.

____________________  ______________________
Date  Signature

Thank you very much for your participation!
Læs dette før du går i gang

Spørgeskemaet inddelt i forskellige emner:

- Din insulinbehandling
- Dine besøg i diabetesambulatoriet
- Pasningen af din diabetes
- Problemer forbundet med diabetes

Du skal blot svar på spørgsmålene i den rækkefølge de er stillet og følge de instruktioner, der gives undervejs (instruktionerne er skrevet i parentes).

Det er vigtigt,
- at du svarer på alle spørgsmålene
- at du svarer så ærligt som muligt
- at det kun er dig selv, der svarer

Sådan udfylder du spørgeskemaet


Hvis du kommer til at lave en fejl, kan du blot sætte et minus ud for den forkerte markering og derefter udfylde den rigtige cirkel.

Det er vigtigt, at du svarer på alle spørgsmålene. Er der spørgsmål, hvor du har svært ved at finde en svarmulighed, skal du vælge den, der umiddelbart passer bedst.

Hvis du har spørgsmål eller kommentarer, er du meget velkommen til at kontakte:

Vibeke Zoffmann Knudsen
Institut for Almen Medicin
Vennelyst Boulevard 6
8000 Århus C
E-mail: vzk@alm.au.dk
eller på telefon: 8942 6042 hverdage mellem kl. 09.00-15.00.

Mange tak for hjælpen!
7. Hvad er din erhvervsmæssige stilling? (Sæt kun én markering)

I erhverv
- Selvstændig erhvervsdrivende (incl. medhjælpende ægtefælle)
- Funktionær eller tjenestemand (offentlig ansat)
- Funktionær (privat ansat)
- Faglært arbejder
- Specialarbejder eller ikke-faglært arbejder
- Lærling/elev

Ikke i erhverv
- Husmoder
- Folkepensionist
- Rettidsarbejder
- På efterløn
- Arbejdsløs
- På bistandsstøtte
- Studerende, skoleelev
- Andet, skriv hvad:

8. Skriv med dine egne ord, hvad din stillingsbetegnelse er:
(Nøjagtig angivelse: Eksempelvis gårdejer, ikke blot landmand, smedevend, ikke blot smed, kontorchef i skattevæsenen, ikke blot kontorchef)

9. Har du nogle ansatte/underordnede?
- Nej
- Ja, hvor mange?

10. Hvilken skoleuddannelse har du? (Sæt kun én markering)

Går i skole
- 7 eller 8 års skolegang
- 8-9 års skolegang
- 10 års skolegang
- Studenter-, HF-eksamen (incl. HHX, HTX)
- Andet (herunder udenlands skole), skriv hvad:

11. Har du fuldført en erhvervsuddannelse?
(Jævnlig angivelse: Eksempelvis både i efg-uddannelse eller handelsskolernes grunduddannelse (HG))

Ja, specialarbejderuddannelse
- Ja, basisår i efg-uddannelse eller handelsskolernes grunduddannelse (HG)
- Ja, lærlinge-, efg- eller HG-uddannelse
- Ja, anden faglig uddannelse
- Ja, kort, videregående uddannelse, under 3 år
- Ja, mellemlang, videregående uddannelse 3-4 år
- Ja, lang, videregående uddannelse, over 4 år
- Ja, anden uddannelse, skriv hvilken:
- Nej, ingen uddannelse
De følgende spørgsmål handler om din diabetes

12. Hvor gammel var du, da du fik konstateret diabetes? □ □ År

13. Hvor længe har du haft diabetes? □ □ år

14. Hvor ofte forhindrer din diabetes dig i at gennemføre dine normale aktiviteter (fx ikke at kunne tage på arbejde, arbejde hjemme, gå i skole eller besøge venner)

Aldrig 1 2 3 4 5 6 7 Ofte

15. Hvordan vil du vurdere din forståelse af diabetes og behandlingen af den?

Dårlig 1 2 3 4 5 6 7 Virkelig god

16. Hvor god er du til at indpasse din diabetes i dit liv på en positiv måde?

Slet ikke i stand til det 1 2 3 4 5 6 7 Virkelig god

De følgende spørgsmål handler om din insulinbehandling

17. Hvordan tager du din insulin?

○ Jeg bruger pen
○ Jeg har pumpe

Angiv dit nuværende insulinforbrug for en typisk dag

Morgen Hurtigtvirkende □ □ □ □ □ □ □ Langsomtvirkende □ □ □ □ □ □ □ Blandingsinsulin □ □ □ □ □ □ □

Middag Hurtigtvirkende □ □ □ □ □ □ □ Langsomtvirkende □ □ □ □ □ □ □ Blandingsinsulin □ □ □ □ □ □ □

Af ten Hurtigtvirkende □ □ □ □ □ □ □ Langsomtvirkende □ □ □ □ □ □ □ Blandingsinsulin □ □ □ □ □ □ □

Sengtid Hurtigtvirkende □ □ □ □ □ □ □ Langsomtvirkende □ □ □ □ □ □ □ Blandingsinsulin □ □ □ □ □ □ □

Ekstra Hurtigtvirkende □ □ □ □ □ □ □ Langsomtvirkende □ □ □ □ □ □ □ Blandingsinsulin □ □ □ □ □ □ □

Kun hvis du har pumpe Antal enheder

Basisdosis □ □ □ □ □ □ □ (Måltidsdosis skrives ovenfor)

Hvor tit sker det, at du glemmer/undlader at tage din insulin?

○ Dagen
○ En til flere gange om ugen
○ En til flere gange om måneden
○ Aldrig, eller næsten aldrig
19. Måler du dit eget blodsukker?
   ○ Ja  ○ Nej (Hvis nej, gå til spørgsmål 20)

20. Hvor mange gange har du målt dit blodsukker i løbet af de sidste 7 dage?
   □ □ Gange

21. Hvor mange gange har du målt dit blodsukker i løbet af den sidste måned?
   □ □ Gange

22. Hvor tit justerer du din insulindosis afhængig af dine målinger?
   ○ Dagligt
   ○ En til flere gange om ugen
   ○ En til flere gange om måneden
   ○ Aldrig eller næsten aldrig

23. Har du sidst du var i ambulatoriet, drøftet resultaterne af dine hjemmemålinger med sundhedspersonalet?
   ○ Ja  ○ Nej  ○ Husker det ikke

24. Har du fået undervisning i, hvordan du kan justere din insulin på baggrund af dine blodsukkermålinger?
   ○ Ja  ○ Nej  ○ Ved ikke

25. Hvor sikker føler du dig i at justere din insulindosis?
   ○ Meget usikker
   ○ Rimelig usikker
   ○ Rimelig sikker
   ○ Meget sikker


Arbejd hurtigt og besvar alle punkterne så godt du kan.

<table>
<thead>
<tr>
<th>26. Jeg føler, at sundhedspersonalet præsenterede mig for valg og muligheder med hensyn til at håndtere min diabetes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Meget uenig  ○ Noget uenig  ○ Lidt uenig  ○ Neutral  ○ Lidt enig  ○ Noget enig  ○ Meget enig</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>27. Jeg føler mig forstået af sundhedspersonalet med hensyn til min diabetes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Meget uenig  ○ Noget uenig  ○ Lidt uenig  ○ Neutral  ○ Lidt enig  ○ Noget enig  ○ Meget enig</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>28. Sundhedspersonalet udykker tillid til, at jeg kan følge de ændringer, der er nødvendige for at styre min diabetes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Meget uenig  ○ Noget uenig  ○ Lidt uenig  ○ Neutral  ○ Lidt enig  ○ Noget enig  ○ Meget enig</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>29. Sundhedspersonalet opmuntrer mig til at stille spørgsmål om min diabetes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Meget uenig  ○ Noget uenig  ○ Lidt uenig  ○ Neutral  ○ Lidt enig  ○ Noget enig  ○ Meget enig</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>30. Sundhedspersonalet prøver at forstå, hvordan jeg ser på min diabetes, inden de foreslår en ny måde at gøre tingene på.</th>
</tr>
</thead>
<tbody>
<tr>
<td>○ Meget uenig  ○ Noget uenig  ○ Lidt uenig  ○ Neutral  ○ Lidt enig  ○ Noget enig  ○ Meget enig</td>
</tr>
</tbody>
</table>
Spørgeskema
Maj 2001

Der er mange forskellige grunde til, at patienter tager deres medicin, checker deres blodsukker, følger deres diæt eller motionerer regelmæssigt. Vi beder dig overveje følgende udsagn og angive, i hvor høj grad du er enig eller uenig i hvert udsagn ved hjælp af skalaen herunder.

A. Jeg tager min diabetesmedicin og/eller måler mit blodsukker, fordi:

<table>
<thead>
<tr>
<th>Meget uenig</th>
<th>Noget uenig</th>
<th>Lidt uenig</th>
<th>Neutral</th>
<th>Lidt enig</th>
<th>Noget enig</th>
<th>Meget enig</th>
</tr>
</thead>
</table>
31. Andre mennesker ville blive vrede på mig, hvis jeg ikke gjorde det. | o | o | o | o | o | o |
32. Det er en personlig udfordring for mig at gøre det. | o | o | o | o | o | o |
33. Jeg ved egentlig ikke hvorfor jeg prøver, det nyter alligevel ikke. | o | o | o | o | o | o |
34. Jeg tror personligt, at min helbred vil forbedres, hvis jeg har min diabetes under kontrol. | o | o | o | o | o | o |
35. Jeg ville føle skyld, hvis jeg ikke gjorde det, som min læge siger. | o | o | o | o | o | o |
36. Jeg vil gerne have, at min læge syner, jeg er en god patient. | o | o | o | o | o | o |
37. Jeg ville have det dårligt med mig selv, hvis jeg ikke gjorde det. | o | o | o | o | o | o |
38. Det er spændende at prøve at holde mit blodsukker inden for et område, der er godt for mit helbred. | o | o | o | o | o | o |
39. Jeg ønsker ikke, at andre mennesker skal blive skuffede over mig. | o | o | o | o | o | o |

B. Grunden til, at jeg følger min diæt og motionerer regelmæssigt, er at:

<table>
<thead>
<tr>
<th>Meget uenig</th>
<th>Noget uenig</th>
<th>Lidt uenig</th>
<th>Neutral</th>
<th>Lidt enig</th>
<th>Noget enig</th>
<th>Meget enig</th>
</tr>
</thead>
</table>
40. Jeg ville gøre andre kede af det, hvis jeg ikke gjorde det. | o | o | o | o | o | o |
41. Jeg tror personligt på, at disse forhold er vigtige for at forblive sund og rask. | o | o | o | o | o | o |
42. Jeg ville skamme mig over mig selv, hvis jeg ikke gjorde det. | o | o | o | o | o | o |
43. Det er lettere at gøre, hvad jeg færbesked på, end selv at skulle tænke over det. | o | o | o | o | o | o |
44. Jeg har tænkt grundigt på at følge min diæt og motionere og tror på, at det er det rigtige at gøre. | o | o | o | o | o | o |
45. Jeg vil gerne have, at andre skal se, at jeg kan følge min diæt og holde mig i god form. | o | o | o | o | o | o |
46. Jeg ville ikke gøre. Jeg gør det vel kun, fordi min læge har sagt, at jeg skal. | o | o | o | o | o | o |
47. Jeg føler personligt, at det er bedst for mig at være opmærksom på min diæt og motion. | o | o | o | o | o | o |
48. Jeg ville føle skyld, hvis jeg ikke var opmærksom på min diæt og motion. | o | o | o | o | o | o |
49. Regelmæssig motion og overholdelse af diæt er valg, jeg virkelig ønsker at træffe. | o | o | o | o | o | o |
50. Det er en udfordring at lære, hvordan man lever med diabetes. | o | o | o | o | o | o |
51. Jeg er ikke sikker på, hvorfor jeg egentlig overholder min diæt eller motionerer regelmæssigt; jeg må vente og se tiden an. | o | o | o | o | o | o |
**Spørgeskema**  
**Maj 2001**  
**Løbenummer**

Vi beder dig læse de følgende udsagn og sætte en markering i cirklen under det svar, der bedst passer til din grad af enighed.

<table>
<thead>
<tr>
<th>52. Jeg føler mig tryg ved min evne til at klare min diabetes.</th>
<th>Meget uenig</th>
<th>Noget uenig</th>
<th>Lidt neutral</th>
<th>Lidt enig</th>
<th>Noget enig</th>
<th>Meget enig</th>
</tr>
</thead>
<tbody>
<tr>
<td>53. Jeg føler mig i stand til at håndtere min diabetes nu.</td>
<td>Meget uenig</td>
<td>Noget uenig</td>
<td>Lidt neutral</td>
<td>Lidt enig</td>
<td>Noget enig</td>
<td>Meget enig</td>
</tr>
<tr>
<td>54. Jeg er i stand til at varetage den rutinemæssige pasning af min diabetes nu.</td>
<td>Meget uenig</td>
<td>Noget uenig</td>
<td>Lidt neutral</td>
<td>Lidt enig</td>
<td>Noget enig</td>
<td>Meget enig</td>
</tr>
<tr>
<td>55. Jeg føler mig tryg ved at diskutere min diabetes med sundhedspersonalet.</td>
<td>Meget uenig</td>
<td>Noget uenig</td>
<td>Lidt neutral</td>
<td>Lidt enig</td>
<td>Noget enig</td>
<td>Meget enig</td>
</tr>
<tr>
<td>56. Jeg er i stand til at møde den udfordring, det er at styre min diabetes.</td>
<td>Meget uenig</td>
<td>Noget uenig</td>
<td>Lidt neutral</td>
<td>Lidt enig</td>
<td>Noget enig</td>
<td>Meget enig</td>
</tr>
</tbody>
</table>

Hvilke af følgende diabetesforhold er for tiden et problem for dig?

Sæt én markering i cirklen under det svar, der bedst dækker dit svar. Du bedes venligst besvare alle spørgsmålene.

| 63. At du ikke ved, om udsving i humør eller følelser hænger sammen med din diabetes? | Ikke et problem | Mindre problem | Moderat problem | Alvorligt problem |
| 64. At du føler, at din diabetes tager magten fra dig? | Ikke et problem | Mindre problem | Moderat problem | Alvorligt problem |
| 65. At du er bekymret for reaktioner på for lavt blodsukker? | Ikke et problem | Mindre problem | Moderat problem | Alvorligt problem |
| 68. At du er bekymret for fremtidens og risikoen for alvorlige komplikationer? | Ikke et problem | Mindre problem | Moderat problem | Alvorligt problem |
| 75. At kunne magte komplikationer til diabetes? | Ikke et problem | Mindre problem | Moderat problem | Alvorligt problem |
Tilsagn

Jeg bekræfter hermed, at jeg efter at have modtaget information om projektet: "Videre i Livet med Diabetes", ønsker at deltage i den beskrevne undersøgelse.

Jeg vil gerne deltage i kurset og inviteres til orienteringsmøde:  

- [ ] Ja
- [x] Nej

En forudsætning for, at jeg kan deltage er: ________________________________

Hvis nej, besvar venligst følgende spørgsmål:

- [ ] Jeg kan ikke afsætte tid til det i den aktuelle periode
- [ ] Jeg vil ikke bruge så meget tid på min diabetes
- [ ] Jeg kan ikke på de pågældende tidspunkter
- [ ] Jeg er godt tillfreds med min situation og ønsker ikke noget ændret
- [ ] Jeg ønsker ikke at være i en gruppe, men ville gerne have haft tilbuddet individuelt
- [ ] Jeg tror ikke på, at jeg kan få gavn af et sådant tilbud
- [ ] Andre grunde, beskriv venligst ________________________________
- [ ] Jeg er i tvivl og vil gerne kontaktes på telefonnummer: ________________________________

Jeg er informeret om, at det er frivilligt at deltage, og at jeg på ethvert tidspunkt og uden begrundelse kan ændre min beslutning uden, at det vil påvirke min nuværende eller fremtidige pleje og behandling.

_________________________  ____________________________
Dato                  Underskrift

Mange tak for hjælpen!
Read this before completing the questionnaire

This questionnaire is a follow-up to the one you completed in 2001. You will be asked almost identical questions once more to see how you are at the moment. Please complete the form without referring to your previous answers if you have kept a copy of the first questionnaire.

The questions relate to the following topics:
- Your insulin treatment
- Your visits to the outpatient clinic
- Managing your diabetes
- Problems related to diabetes.

You should answer the questions in the sequence in which they are presented in the questionnaire and follow any instructions given (instructions appear in parenthesis).

It is essential,
- that you answer all the questions
- that you answer as honestly as possible
- that you answer the questions yourself

How to complete the questionnaire

Mark the circle corresponding to the answer of your choice. Make sure your marks fill the circles. Marks covering the original circle are accepted. Please use a black marker as the questionnaire is read mechanically.

Correct: ✔
Incorrect: ✗

In some questions you will be instructed to write digits and letters. Please write as clearly as possible and try to make your writing resemble these examples:

1 2 3 4 5 6 7 8 9 0

If you make a mistake, simply add a minus sign by the incorrect marking and fill out the correct circle.

It is important that you answer all the questions. If you cannot find an option covering the answer you would prefer, simply select the one that seems to fit your opinion best.

For any further questions or comments, feel free to contact:
Vibeke Zoffmann Knudsen
Department of General Practice, Vennelyst Boulevard 6, 8000 Århus C
E-mail: vzk@alm.au.dk
or by phone 8942 6042 - Working days from 9am. to 3pm.

Thank you very much for your help!
9. How often does your diabetes prevent you from doing your normal daily activities (could not work or go to school or visit friends)? (Circle one number)
   - Never
   - Frequently

10. How would you rate your understanding of diabetes and its treatment? (Circle one number)
    - Poor
    - Excellent

11. Please circle the number that indicates how able you are to fit diabetes into your life in a positive manner. (Circle one number)
    - Not at all able
    - Very able

13. Which insulin type(s) do you use?
    - Fast acting
    - Slow acting
    - Mixed insulin

State your current insulin consumption on an average day

<table>
<thead>
<tr>
<th>Time</th>
<th>Fast acting</th>
<th>Slow acting</th>
<th>Mixed insulin</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morning</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Midday</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evening</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bedtime</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extra</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Only if you use a pump</td>
<td>Basal rate</td>
<td>(Indicate meal dose at previous question)</td>
<td></td>
</tr>
</tbody>
</table>

How often do you forget/refrain from taking your insulin?

- Every day
- One or more times a week
- One or more times a month
- Never or almost never
14. Do you measure your blood sugar?
   ○ Yes    ○ No (If no, please proceed to question 19)

15. How many times have you measured your blood sugar during the last 7 days?

16. How many times have you measured your blood sugar during the last month?

17. How often do you adjust your insulin dose according to your measurements?
   ○ Every day
   ○ One or more times a week
   ○ One or more times a month
   ○ Never or almost never

18. Have you discussed the results of your home measurements with the health staff during your last visit at the outpatient clinic?
   ○ Yes    ○ Nej    ○ I do not remember

19. Have you received any training in adjusting your insulin dose according to your blood sugar measurements?
   ○ Yes    ○ No    ○ I do not know

20. Are you confident with adjusting your insulin dose?
   ○ Not confident at all
   ○ Not very confident
   ○ Fairly confident
   ○ Very confident

21. I feel that course participants and leaders offered me choices and opportunities regarding the handling of my diabetes.

22. I felt that course participants and leaders understood my situation regarding diabetes.

23. Course participants and leaders expressed confidence that I would be able to make the changes necessary to control my diabetes.

24. Course participants and leaders encouraged me to ask questions regarding my diabetes.

25. Course participants and leaders tried to understand how I perceived my diabetes before suggesting alternative solutions.

26. Course participants and leaders encouraged me to think carefully about my diabetes.
Next you will be presented to a series of statements concerning your perception of other groups of staff at your last visit to the outpatient diabetes clinic. Health staff deal with patients in different ways, and we would like to know how you perceived the health staff when discussing your diabetes. Your answers will remain confidential. Please be honest and candid. Answer by marking the circle corresponding to your degree of agreement with each statement.

27. I feel that course participants and leaders offered me choices and opportunities regarding the handling of my diabetes. 

28. I felt that course participants and leaders understood my situation regarding diabetes.

29. Course participants and leaders expressed confidence that I would be able to make the changes necessary to control my diabetes.

30. Course participants and leaders encouraged me to ask questions regarding my diabetes.

31. Course participants and leaders tried to understand how I perceived my diabetes before suggesting alternative solutions.

32. Course participants and leaders encouraged me to think carefully about my diabetes.

33. Other people would be mad at me if I didn’t.

34. I find it a personal challenge to do so.

35. I don’t know why I’d try - I won’t be successful.

36. I personally believe that controlling my diabetes will improve my health.

37. I would feel guilty if I didn’t do what my doctor said.

38. I want my doctor to think I’m a good patient.

39. I would feel bad about myself if I didn’t.

40. It’s exciting to try to keep my glucose in a healthy range.

41. I don’t want other people to be disappointed in me.
### B. The reason I follow my diet and exercise regularly is that:

<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
<th>Strongly disagree</th>
<th>Moderately disagree</th>
<th>Slightly disagree</th>
<th>Neutral</th>
<th>Slightly agree</th>
<th>Moderately agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>42.</td>
<td>Other people would be upset with me if I didn’t.</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>43.</td>
<td>I personally believe that these are important in remaining healthy.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>44.</td>
<td>I would be ashamed of myself if I didn’t.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>45.</td>
<td>It is easier to do what I’m told than to think about it.</td>
<td></td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>46.</td>
<td>I’ve carefully thought about my diet and exercising and believe it’s the right thing to do.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>47.</td>
<td>I want others to see that I can follow my diet and stay fit.</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>48.</td>
<td>I don’t know why; I’d just do it because my doctor said to.</td>
<td></td>
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</tr>
<tr>
<td>49.</td>
<td>I feel personally that watching my diet and exercising are the best things for me.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>50.</td>
<td>I’d feel guilty if I didn’t watch my diet and exercise.</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>51.</td>
<td>Exercising regularly and following my diet are choices I really want to make.</td>
<td></td>
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</tr>
<tr>
<td>52.</td>
<td>It’s a challenge to learn how to live with diabetes.</td>
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<td></td>
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<tr>
<td>53.</td>
<td>I’m not sure why I’d follow a diet or exercise, I’ll wait and see.</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

### Please read each item and mark the circle corresponding the number that indicates your level of agreement with that statement.

<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
<th>Strongly disagree</th>
<th>Moderately disagree</th>
<th>Slightly disagree</th>
<th>Neutral</th>
<th>Slightly agree</th>
<th>Moderately agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>54.</td>
<td>I feel confident in my ability to manage my diabetes.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>55.</td>
<td>I now feel capable of handling my diabetes.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>56.</td>
<td>I am able to do my own routine diabetic care now.</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>57.</td>
<td>I feel confident discussing my diabetes with my care provider.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>58.</td>
<td>I am able to meet the challenge of controlling my diabetes.</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

### Which of the following diabetes issues are currently a problem for you? Mark the circle corresponding the number that gives the best answer for you. Please provide an answer for each question.

<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
<th>Not a problem</th>
<th>Minor problem</th>
<th>Moderate problem</th>
<th>Somewhat serious problem</th>
<th>Serious problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>59.</td>
<td>Not having clear and concrete goals for your diabetes care?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60.</td>
<td>Feeling discouraged with your diabetes treatment plan?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>61.</td>
<td>Feeling scared when you think about living with diabetes?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>62.</td>
<td>Uncomfortable social situations related to your diabetes care (e.g., people telling you what to eat)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>63.</td>
<td>Feelings of deprivation regarding food or meals?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>64.</td>
<td>Feeling depressed when you think about living with diabetes?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Question</td>
<td>Not a problem</td>
<td>Minor problem</td>
<td>Moderate problem</td>
<td>Somewhat serious problem</td>
<td>Serious problem</td>
<td></td>
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<tr>
<td>------------------------------------------------------------------------</td>
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<td></td>
</tr>
<tr>
<td>65. Not knowing if your mood or feelings are related to your diabetes?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
</tr>
<tr>
<td>66. Feeling overwhelmed by your diabetes?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
</tr>
<tr>
<td>67. Worrying about low blood sugar reactions?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
</tr>
<tr>
<td>68. Feeling angry when you think about living with diabetes?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
</tr>
<tr>
<td>69. Feeling constantly concerned about food and eating?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
</tr>
<tr>
<td>70. Worrying about the future and the possibility of serious complications?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
</tr>
<tr>
<td>71. Feelings of guilt or anxiety when you get off track with your diabetes management?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
</tr>
<tr>
<td>72. Not &quot;accepting&quot; your diabetes?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
</tr>
<tr>
<td>73. Feeling unsatisfied with your diabetes physician?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
</tr>
<tr>
<td>74. Feeling that diabetes is taking up too much of your mental and physical energy every day?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
</tr>
<tr>
<td>75. Feeling alone with your diabetes?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
</tr>
<tr>
<td>76. Feeling that your friends and family are not supportive of your diabetes management efforts?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
</tr>
<tr>
<td>77. Coping with complications of diabetes?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
</tr>
<tr>
<td>78. Feeling &quot;burned out&quot; by the constant effort needed to manage diabetes?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td></td>
</tr>
</tbody>
</table>

Please only answer the next series of questions if you have signed up for the course "Life skills with Type 1 diabetes" to be held in autumn 2002.

79. I still want to participate in the course held in the autumn of 2002:
   - Yes, I want to participate (proceed to question 80)
   - No
      (proceed to question 81)

80. I can participate on all the scheduled course days.
   - Yes
   - No
      I will not be able to participate on the following dates:

   Date(s): / / / / / / / /

81. I have changed my mind and decided not to participate in the course held during the autumn of 2002:
   - Because I do not need the course
   - Because I cannot find the time to participate
   - Other reasons

Please only answer question 82 if you have turned down the latest invitation to participate.

82. I would like to be invited if another course is held at a later date:
   - No
   - Yes

   If "yes" - I would prefer the course to be:
   - An individual course
   - A group-based course
   - It is not important to me if the course is individual or group-based
Participation in projects may have positive as well as negative effects. Please answer questions 83-85 regardless of your degree of participation in the project (including filling in the questionnaire).

83. Has your participation in this project had negative effects on you?
   - Yes  Describe the negative effect(s) ____________________________________________
   - No
   - I do not know

84. Has your participation in this project had positive effects on you?
   - Yes  Describe the positive effect(s) ____________________________________________
   - No
   - I do not know

85. Estimate the projects overall effect on you!
   - Substantial negative effect
   - Negative effect
   - Limited negative effect
   - No effect
   - Limited positive effect
   - Positive effect
   - Substantial positive effect

86. My benefit from the course may be summarised in the following sentence: __________________________
   __________________________
   __________________________
   __________________________

For questions etc. I can be reached at the following phone no.:

Private __________________________

Work __________________________

Thank you very much for your participation!
**Spørgeskema**

Maj 2001 -

Læs dette før du går i gang

Spørgeskemaet inddeles i forskellige emner:

- Din insulinbehandling
- Dine besøg i diabetesambulatoriet
- Pasningen af din diabetes
- Problemer forbundet med diabetes

Du skal blot sva re på spørgsmålne i den rækkefølge de er stillet og følge de instruktioner, der gives undenuvejs (instruktionerne er skrevet i parentes).

Det er vigtigt,
- at du svarer på alle spørgsmålene
- at du svarer så ærligt som muligt
- at det kun er dig selv, der svarer

Sådan udfylder du spørgeskemaet


<table>
<thead>
<tr>
<th>Rigtigt:</th>
<th>☐</th>
</tr>
</thead>
<tbody>
<tr>
<td>Forkert:</td>
<td>☒</td>
</tr>
</tbody>
</table>

Under enkelte spørgsmål bliver du bedt om at skrive tal og bogstaver. Skriv så tydeligt som muligt og helst så de ligner nedenstående eksempler.

1 2 3 4 5 6 7 8 9 0

Hvis du kommer til at lave en fejl, kan du blot sætte et minus ud for den forkerte markering og derefter udfylde den rigtige cirkel.

Det er vigtigt, at du svarer på alle spørgsmålene. Er der spørgsmål, hvor du har svært ved at finde en svarmulighed, der passer præcist, skal du vælge den, der umiddelbart passer bedst.

Hvis du har spørgsmål eller kommentarer, er du meget velkommen til at kontakte

Vibeke Zoffmann Knudsen
Institut for Almen Medicin
Vennerøg Boulevard 6
8000 Århus C
E-mail: vzk@alm.au.dk
eller på telefon: 8942 6042
hverdage mellem kl. 09.00-15.00.

Mange tak for hjælpen!
7. Hvad er din erhvervsmæssige stilling? (Sæt kun én marking)

- Selvstændig erhvervsdrivende (incl. medhjælpende ægtefælle)
- Funktionær eller tjenestemand (offentlig ansat)
- Funktionær (privat ansat)
- Faglært arbejder
- Specialarbejder eller ikke-faglært arbejder
- Lærling/elev

Ikke i erhverv
- Husmoder
- Folkepensionist
- Søsporets pensionist
- På efterløn
- Arbejdsløs
- På biståndshjælp
- Studerende, skoleelev
- Andet, skriv hvad:

8. Skriv med dine egne ord, hvad din stillingsbetegnelse er:
(Nøjagtig angivelse: Eksempelvis gårdejer, ikke blot landmand, smedensvend, ikke blot smed, kontorchef i skattevæsenet, ikke blot kontorchef)

9. Har du nogle ansatte/underordnede?
- Nej
- Ja, hvor mange?

10. Hvilken skoleuddannelse har du? (Sæt kun én marking)

- Går i skole
- 7 eller 8-9 års skolegang
- 10 års skolegang
- Studenter-, HF-eksamen (incl. HHX, HTX)
- Andet (herunder udenlandsk skole), skriv hvad:

11. Har du fuldført en erhvervsuddannelse? (Sæt kun én marking)

- Ja, specialarbejderuddannelse
- Ja, basisår i efg-uddannelse eller handelskolerens grunduddannelse (HG)
- Ja, lærlinge-, efg- eller HG-uddannelse
- Ja, anden faglig uddannelse
- Ja, kort, videregående uddannelse, under 3 år
- Ja, mellemlæng. videregående uddannelse 3-4 år
- Ja, lang, videregående uddannelse, over 4 år
- Ja, anden uddannelse, skriv hvilken:
- Nej, ingen uddannelse
12. Hvor gammel var du, da du fik konstateret diabetes? [ ] År

13. Hvor længe har du haft diabetes? [ ] år

14. Hvor ofte forhindrer din diabetes dig i at gennemføre dine normale aktiviteter (fx ikke at kunne tage på arbejde, arbejde hjemme, gå i skole eller besøge venner)

   Aldrig 1 2 3 4 5 6 7 Ofte

15. Hvordan vil du vurdere din forståelse af diabetes og behandlingen af den?

   Dårlig 1 2 3 4 5 6 7 Virkelig god

16. Hvor god er du til at indpasse din diabetes i dit liv på en positiv måde?

   Slet ikke i stand til det 1 2 3 4 5 6 7 Virkelig god

17. Hvordan tager du din insulin?

   ○ Jeg bruger pen
   ○ Jeg har pumpe

18. Hvilken insulin(r) bruger du?

   Angiv dit nuværende insulinforbrug for en typisk dag

   Antal enheder

   Hurtigtvirkende Langsomtvirkende Blandingsinsulin

   Morgen Hurtigtvirkende Langsomtvirkende Blandingsinsulin

   Middag Hurtigtvirkende Langsomtvirkende Blandingsinsulin

   Af ten Hurtigtvirkende Langsomtvirkende Blandingsinsulin

   Sengetid Hurtigtvirkende Langsomtvirkende Blandingsinsulin

   Ekstra Hurtigtvirkende Langsomtvirkende Blandingsinsulin

   Basisdosis Antal enheder

   (Måltidsdosis skrives ovenfor)

   Hvor tit sker det, at du glemmer/undlader at tage din insulin?

   ○ Dagligt
   ○ En til flere gange om ugen
   ○ En til flere gange om måneden
   ○ Aldrig, eller næsten aldrig
19. Måler du dit eget blodsukker?
   - Ja
   - Nej (Hvis nej, gå til spørgsmål 20)

20. Hvor mange gange har du målt dit blodsukker i løbet af de sidste 7 dage?

21. Hvor mange gange har du målt dit blodsukker i løbet af den sidste måned?

22. Hvor tit justerer du din insulindosis afhængig af dine målinger?
   - Dagligt
   - En til flere gange om ugen
   - En til flere gange om måneden
   - Aldrig eller næsten aldrig

23. Har du sidst været i ambulatoriet, drøftet resultaterne af dine hjemmemålinger med sundhedspersonalet?
   - Ja
   - Nej
   - Husker det ikke

24. Har du fået undervisning i, hvordan du kan justere din insulin på baggrund af dine blodsukkermålinger?
   - Ja
   - Nej
   - Ved ikke

25. Hvor sikker føler du dig i at justere din insulindosis?
   - Meget usikker
   - Rimelig usikker
   - Rimelig sikker
   - Meget sikker

26. Jeg føler, at sundhedspersonalet præsenterede mig for valg og muligheder med hensyn til at håndtere min diabetes.

27. Jeg føler mig forstået af sundhedspersonalet med hensyn til min diabetes.

28. Sundhedspersonalet udtrykker tillid til, at jeg kan foretage de ændringer, der er nødvendige for at styre min diabetes.

29. Sundhedspersonalet opmuntrer mig til at stille spørgsmål om min diabetes.

30. Sundhedspersonalet prøver at forstå, hvordan jeg ser på min diabetes, inden de foreslår en ny måde at gøre tingene på.
Der er mange forskellige grunde til, at patienter tager deres medicin, checker deres blodsukker, følger deres diæt eller motionerer regelmæssigt.

Vi beder dig overveje følgende udsagn og angive, i hvor høj grad du er enig eller uenig i hvert udsagn ved hjælp af skalaen herunder.

**A. Jeg tager min diabetesmedicin og/eller måler mit blodsukker, fordi:**

<table>
<thead>
<tr>
<th>Udsagn</th>
<th>Meget uenig</th>
<th>Noget uenig</th>
<th>Lidt uenig</th>
<th>Neutral</th>
<th>Lidt enig</th>
<th>Noget enig</th>
<th>Meget enig</th>
</tr>
</thead>
<tbody>
<tr>
<td>31. Andre mennesker ville blive vrede paa mig, hvis jeg ikke gjorde det.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>32. Det er en personlig udfordring for mig at gøre det.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>33. Jeg ved egentlig ikke hvorfra jeg prøver, det nyter alligevel ikke.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>34. Jeg tror personligt, at mit helbred vil forbedres, hvis jeg har min diabetes under kontrol.</td>
<td>o</td>
<td>o</td>
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<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
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<tr>
<td>35. Jeg ville føle skylt, hvis jeg ikke gjorde det, som min læge siger.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
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<tr>
<td>36. Jeg vil gerne have, at min læge synes, jeg er en god patient.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>37. Jeg ville have det dårligt med mig selv, hvis jeg ikke gjorde det.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>38. Det er spændende at prøve at holde mit blodsukker inden for et område, der er godt for mit helbred.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>39. Jeg ønsker ikke, at andre mennesker skal træffe over mig.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
</tbody>
</table>

**B. Grunden til, at jeg følger min diæt og motionerer regelmæssigt, er at:**

<table>
<thead>
<tr>
<th>Udsagn</th>
<th>Meget uenig</th>
<th>Noget uenig</th>
<th>Lidt uenig</th>
<th>Neutral</th>
<th>Lidt enig</th>
<th>Noget enig</th>
<th>Meget enig</th>
</tr>
</thead>
<tbody>
<tr>
<td>40. Jeg ville gøre andre kede af det, hvis jeg ikke gjorde det.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>41. Jeg tror personligt på, at disse forhold er vigtige for at forblive sund og rask.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>42. Jeg ville skamme mig over mig selv, hvis jeg ikke gjorde det.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>43. Det er lettere at gøre, hvad jeg får besked på, end selv at skulle tænke over det.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>44. Jeg har tænkt grundigt på at følge min diæt og motionere og tror på, at det er det rigtige at gøre.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>45. Jeg vil gerne have, at andre skal se, at jeg kan følge min diæt og holde mig i god form.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>46. Jeg ved ikke hvorfra. Jeg gør det vel kun, fordi min læge har sagt, at jeg skal.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>47. Jeg føler personligt, at det er bedst for mig at være opmærksom på min diæt og motion.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>48. Jeg ville føle skylt, hvis jeg ikke var opmærksom på min diæt og motion.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>49. Regelæggelse som er vigtig for mig, jeg vil gerne overholde min diæt og motion.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>50. Det er en udfordring at lære, hvordan man lever med diabetes.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>51. Jeg er ikke sikker på, hvorfra jeg egentlig overholder min diæt eller motionerer regelmæssigt; jeg må vente og se tiden an.</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
</tbody>
</table>
Vi beder dig læse de følgende udsagn og sætte en markering i cirklen under det svar, der bedst passer til din grad af enighed.

52. Jeg føler mig tryg ved min evne til at klare min diabetes. ○ ○ ○ ○ ○ ○ ○
53. Jeg føler mig i stand til at håndtere min diabetes nu. ○ ○ ○ ○ ○ ○ ○
54. Jeg er i stand til at varetage den rutinemæssige pasning af min diabetes nu. ○ ○ ○ ○ ○ ○ ○
55. Jeg føler mig tryg ved at diskutere min diabetes med sundhedspersonalet. ○ ○ ○ ○ ○ ○ ○
56. Jeg er i stand til at møde den udfordring, der er at styre min diabetes. ○ ○ ○ ○ ○ ○ ○

Hvilke af følgende diabetesforhold er for tiden et problem for dig?

Sæt én markering i cirklen under det svar, der bedst dækker dit svar. Du bedes venligst besvare alle spørgsmålene.

57. At du ikke har klare og konkrete mål for pasningen af din diabetes? ○ ○ ○ ○ ○ ○ ○
58. At du føler dig opgivende over planen for din diabetesbehandling? ○ ○ ○ ○ ○ ○ ○
59. At du føler dig skræmt ved tanken om at leve med diabetes? ○ ○ ○ ○ ○ ○ ○
60. Ubehagelige situationer i forbindelse med din diabetes? (fx at folk trosler dig, hvad du bør spise) ○ ○ ○ ○ ○ ○ ○
61. At du føler afsavn med hensyn til mad og måltider? ○ ○ ○ ○ ○ ○ ○
62. At du føler dig nedtrykt ved tanken om at leve med diabetes? ○ ○ ○ ○ ○ ○ ○
63. At du ikke ved, om udsving i humør eller følelser hænger sammen med din diabetes? ○ ○ ○ ○ ○ ○ ○
64. At du føler, at din diabetes tager magten fra dig? ○ ○ ○ ○ ○ ○ ○
65. At du er bekymret for reaktioner på for lavt blodsukker? ○ ○ ○ ○ ○ ○ ○
66. At du føler vrede ved tanken om at leve med diabetes? ○ ○ ○ ○ ○ ○ ○
67. At du konstant er optaget af mad og overholdelse af måltider? ○ ○ ○ ○ ○ ○ ○
68. At du er bekymret for fremtiden og risikoen for alvorlige komplikationer? ○ ○ ○ ○ ○ ○ ○
69. At du føler skyld eller ængstelse, hvis du ikke har overholdt principperne for din diabetesbehandling? ○ ○ ○ ○ ○ ○ ○
70. At du ikke "accepterer" din diabetes? ○ ○ ○ ○ ○ ○ ○
71. At du føler dig utilfreds med lægerne, der har med din diabetes at gøre? ○ ○ ○ ○ ○ ○ ○
72. At du føler, at din diabetes tager for meget af din energi mentalt og fysisk i hverdagen? ○ ○ ○ ○ ○ ○ ○
73. At du føler dig alene med din diabetes? ○ ○ ○ ○ ○ ○ ○
74. At du føler, at dine venner og din familie ikke støtter dig i dine bestrebelser på at passe din diabetes? ○ ○ ○ ○ ○ ○ ○
75. At kunne magte komplikationer til diabetes? ○ ○ ○ ○ ○ ○ ○
76. At du føler dig "udbrændt" af den indsats, der konstant skal til for at passe din diabetes? ○ ○ ○ ○ ○ ○ ○
Tilsagn

Jeg bekræfter hermed, at jeg efter at have modtaget information om projektet: "Videre i Livet med Diabetes", ønsker at deltage i den beskrevne undersøgelse.

Jeg vil gerne deltage i kurset og inviteres til orienteringsmøde:  

○ Ja  ○ Nej

En forudsætning for, at jeg kan deltage er: __________________________________________

Hvis nej, besvar venligst følgende spørgsmål:

○ Jeg kan ikke afsætte tid til det i den aktuelle periode
○ Jeg vil ikke bruge så meget tid på min diabetes
○ Jeg kan ikke på de pågældende tidspunkter
○ Jeg er godt tilfreds med min situation og ønsker ikke noget ændret
○ Jeg ønsker ikke at være i en gruppe, men ville gerne have haft tilbudet individuelt
○ Jeg tror ikke på, at jeg kan få gavn af et sådant tilbud
○ Andre grunde, beskriv venligst________________________________________________
○ Jeg er i tvivl og vil gerne kontaktes på telefonnummer: ____________________________

Jeg er informeret om, at det er frivilligt at deltage, og at jeg på ethvert tidspunkt og uden begrundelse kan ændre min beslutning uden, at det vil påvirke min nuværende eller fremtidige pleje og behandling.

_________________________  ____________________________
Dato                            Underskrift

Mange tak for hjælpen!
Outcome from GSD group course appraised in questionnaire (question 86) by 30 participants one year after and sorted according to Brook’s taxonomy for life skills.

| Appendix E. Table E 2. | 277 |

**Answers one year after GSD group course to the statement:**

“My outcome of group sessions can be summarized in the following sentence:”

<table>
<thead>
<tr>
<th>Interpersonal communication (IPC)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Out-patient visits have become far more professional and rewarding. We know what we are talking about.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Human relation skills (HRS)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Has given a better and far more realistic picture of my own family situation.</td>
<td></td>
</tr>
<tr>
<td>• My trust in professionals has increased.</td>
<td></td>
</tr>
<tr>
<td>• I have met many people in the same situation, which has been interesting. However, I have not changed anything concerning myself</td>
<td></td>
</tr>
<tr>
<td>• I have improved my relationships with the diabetes nurses.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Decision making skills (DMS)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Nice knowing that you are not the only one. Has opened my eyes a bit.</td>
<td></td>
</tr>
<tr>
<td>• I am more conscious of the specific patterns of thinking which I want to change</td>
<td></td>
</tr>
<tr>
<td>• I am more aware of diabetes than before.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Problem solving (PS)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Focus on diabetes, contact with other diabetics, new angles</td>
<td></td>
</tr>
<tr>
<td>• Nice meeting others with long-term diabetes</td>
<td></td>
</tr>
<tr>
<td>• Nice meeting others in the same boat = having had diabetes more than 25 years. Better insight into food. Good up-to-date knowledge about good regulation</td>
<td></td>
</tr>
<tr>
<td>• I have met a lot of positive people who have the same problems with diabetes management. It has made it easier for me to manage my diabetes.</td>
<td></td>
</tr>
<tr>
<td>• I have been reassured that paying proper attention and having factual discussions make it easier to change and live with chronic illness</td>
<td></td>
</tr>
<tr>
<td>• Nice talking to others with diabetes, hearing that their problems are similar to mine. Nice being roused after 34 years with diabetes.</td>
<td></td>
</tr>
<tr>
<td>• Nice meeting others who have had diabetes for many years – learned a lot of practical things</td>
<td></td>
</tr>
<tr>
<td>• Nice solidarity about common problems</td>
<td></td>
</tr>
<tr>
<td>• Have gained insight into problems and constructively exchanged experience with other diabetes patients and with nurses. Insight into others’ problems and good supervision of my own problems. My problems were the same as the others’.</td>
<td></td>
</tr>
<tr>
<td>• I know where to concentrate, where I still now and then give in to the world’s temptations.</td>
<td></td>
</tr>
</tbody>
</table>
### Physical Health (PH)

- I have more energy
- It has been a positive experience, which has improved my regulation more than I expected. It is a matter of changing goals and limits
- I no longer have low blood sugars in the morning.

### Health maintaining skills (HMS)

- I have learned a lot of positive things about managing my diabetes – met people with other diabetes problems, who I could help
- I have a deeper understanding and far more insight in having and living with diabetes.
- I take better care of my diabetes
- I can make and maintain changes in managing diabetes.
- I check blood sugar much more often. It is, easier to control blood sugar
- I have pulled myself together and check my BG far more frequently. I adjust my insulin more myself – which was also my aim for the course
- I do not any longer perceive my blood-sugar device as an enemy. The mere sight of my blood sugar device no longer makes me irritable
- I am far more active about testing blood sugar and adjusting insulin doses
- By checking blood sugars much more often it is easier for me to take care of my blood sugar from day to day.
- I have more knowledge of taking care of my blood sugar in relation to food, exercise and insulin. I have changed insulin – self-control is easier.
- Before the course I thought I could manage my diabetes but I have realized that I was not doing enough. Now I at least know where I need to make an effort. I have since tried to change my behaviour with varying success … for different reasons.
- I think more about diabetes on ordinary days than I used to

### Purpose in life skills (PILS)

- It is a question of shifting personal goals and limits
- On the whole I have more peace of mind.
- It has helped me to recognize and clarify my working situation and my limits but also my possibilities.

### Identity development (ID)

- I realize that I am not the only one who has been struggling with thoughts and feelings such as a bad conscience for years.
- I have come to terms with myself about having diabetes and having to live with diabetes.
- Diabetes does not take up so much space in my life - has ‘changed colour from black to yellow’
- I have learned to understand myself a little better
- I have learned to take responsibility for my own life.
- The training led to personal development, which I see as necessary for better well-being.
Appendix F
To
Doctors at Department C
Aarhus University Hospital

22.05.2000

Briefing 29/5 - 2 pm. at Section 20.

On 1. June I will initiate a PhD project at Section 20 (and at M1 and Aarhus Kommunehospital). The project consists of an intervention study to examine the effect of employing a cross-disciplinary cooperation method with poorly regulated type 1 diabetics.

The initial part of the study concerns the qualitative effect of the cooperation method on patients in routine admission. This part has two functions: 1) it serves as a basis for comparison with 11 previous patient courses from 1996, which were implemented without using the cooperation method; 2) it serves as a pilot project preceding a randomised trial in which the cooperation method will be tested in a guided self-help programme.

The cooperation method has been implemented with nurses at Section 20, who have received theoretical information on the background of the method and who have participated in the adaptation and implementation of the work sheets and communication forms which are the two components comprising the cooperation method. I would have preferred to implement the cooperation method across several disciplines, but have abstained from doing so as I regard this as being too extensive for a PhD study.

The cooperation method is well in keeping with the nurses’ field of interest and, consequently, they will be attributed a pivotal role in the implementation of the method.

Nevertheless, it is vital that the nurses involve the rest of the team. Furthermore, the patients will be monitored during 6 months after the admission, and you will probably be included in the follow-up activities taking place at the outpatient clinic. This is why I would like to inform you of the project and the differences you may expect to encounter in the selected patient courses.

Please find enclosed:
   a) Project description
   b) Time schedule
   c) Work sheets

Yours sincerely,

Vibeke Zoffmann Knudsen
Briefing on the project Life Skills with Diabetes - 31/8, 2.15- 3.00 pm.

As we have agreed that I shall inform you of my Ph.D. project at the time and date stated above, I hereby submit the enclosed abstract.

As you can see, the project includes an intervention study testing a recently implemented cooperation method for poorly regulated type 1 diabetics. The method has been developed on the basis of barriers discovered through the description of the admissions of 11 patients at Section M1 at Aarhus District General Hospital (Århus Kommunehospital) and Section 20 at Aarhus County Hospital (Århus Amtssygehus) during 1996.

The qualitative phase of the project was initiated at the two Sections on 1 June. The current phase tests the method on patients in routine admission. Results will be compared with the admissions of 1996. Furthermore, the qualitative phase will serve as a pilot project ahead of a randomised trial in which the cooperation method will be tested as a (possibly group-based) guided self-help programme.

At this end the cooperation method is implemented by nurses from Section M1. They have received theoretical information on the background of the method and have participated in adaptation and implementation of the work sheets and communication forms which are the two components comprising the cooperation method. I would have preferred to implement the cooperation method across several disciplines, but have abstained from doing so as I regard this as being too wide-ranging for a PhD study. Consequently, I have decided simply to brief you and the dieticians on the project and the differences you may expect to encounter in the selected patient courses.

Please find enclosed abstract.

Yours sincerely,

Vibeke Zoffmann Knudsen


<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
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<tbody>
<tr>
<td>19 September</td>
<td>4-6 pm</td>
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<tr>
<td>26 September</td>
<td>4-6 pm</td>
</tr>
<tr>
<td>3 October</td>
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<tr>
<td>10 October</td>
<td>4-6 pm</td>
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<tr>
<td>24 October</td>
<td>4-6 pm</td>
</tr>
<tr>
<td>31 October</td>
<td>4-6 pm</td>
</tr>
<tr>
<td>7 November</td>
<td>4-6 pm</td>
</tr>
<tr>
<td>14 November</td>
<td>4-6 pm</td>
</tr>
</tbody>
</table>

The draw for participation in the autumn course will take place during briefings in outpatient clinic C’s conference room 4-4.45 pm. on Wednesday 22 August, 29 August or 5 September. Please see enclosed map.

If you agree to participate in the study course, please return the enclosed note with the questionnaire letting me know which meeting you will be attending.

Refer to the brochure “Before making up your mind” for more information about your rights.

Transportation expenses will be covered according to standard rates.

---

**Progressing in life with diabetes - in a new and different way**

Invitation to participate in the scientific study: "Life Skills with Type 1 Diabetes" at Aarhus University Hospital.

**You may participate in the study in two ways:**

1. **You may participate in a guided self-help course:**
   If you wish to participate in the course, please fill in and return the enclosed questionnaire including your signature and confirmation on the final page.

   or

2. **You may participate simply by filling in the enclosed questionnaire:**
   If you wish to participate in this manner, please fill in and return the enclosed questionnaire including your signature, rejection and any comments on the final page.

**If you are in doubt:**

Please contact Vibeke Zoffmann for more information at:
Department for General Medicine
Vennelyst Boulevard 6, 8000 Aarhus C.
Phone: 89426042 or 86295201
Progressing in life with diabetes.
Many experienced type 1 diabetics find it difficult to fit in diabetes into their everyday lives and reach satisfactory blood sugar levels.

In this study we try a different approach. We have developed a method which can be used by everyone to help overcome the difficulties.

The method consists of a number of work sheets which have been tested with great success by a limited number of patients. However, it is not possible to say anything about the methods effect until it has been tested by more patients.

That is why we invite you and 99 others with type 1 diabetes to participate in a scientific study of the method. We have contacted you because, just as the other potential participants, you are a patient at the Aarhus University Hospital and have had type 1 diabetes for more than 4 years with an average HbA1c value of 8.0 or above during the last two years.

To evaluate if the method is efficient, lots will be drawn to decide whether you will participate in group A or B.

Group A
A maximum of 50 persons will be divided into 3 groups which will test the method on a course in the autumn of 2001. The course will be lead by 2 nurses from Dept. M’s day section and by me.

Group B
A maximum of 50 persons wait 1 year for the result of group A’s course and are then offered a similar course if group A has achieved and maintained a definite fall in blood sugar levels.

Who may not participate:
Women who are pregnant or plan to become pregnant during 2001-2 may not participate.

By considering and discussing the method’s work sheets you will:
- Gain a broader understanding of your situation and get new ideas as to how to change exactly those aspects you would like to change.
- Get better at solving problems which seemed difficult in the past.
- Become more aware of what you want to emphasize in your everyday life with diabetes.
- Get better at overcoming the difficulties you relate to, achieving and maintaining lower blood sugar levels.

Before you agree to participate, please consider the following:
- Are you prepared to participate regardless of the outcome of the draw?
- Would you be prepared to give a blood sample to determine your HbA1c in Aug./Sept. 2001 and then every 3 months until Sept. 2002?
- If the draw decides so, would you be able to participate in an 8-week course on Tuesdays and Thursdays 4-6 pm. During September and November of this year (see reverse)?

Anonymity
- Personal information from your questionnaire and work sheets and information concerning your blood samples is confidential and will be kept confidential throughout the study. At the end of the study when the results are published, I will make sure that you cannot be identified from the information published.

You may later decide to leave the study, even if you agree to participate now!
- Participation is completely voluntary and if you choose to participate, you may withdraw from the study at any time without stating the reasons for doing so. If you withdraw from the study, this will in no way affect your future care or treatment.

Yours sincerely,

Vibeke Zoffmann
Registered Nurse, MPH, PhD student
Course Schedule for Groups Meeting on Tuesdays
at Dept. M, Aarhus Kommunehospital.

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
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<tbody>
<tr>
<td>18 September</td>
<td>4 – 6 pm</td>
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<tr>
<td>25 September</td>
<td>4 – 6 pm</td>
</tr>
<tr>
<td>2 October</td>
<td>4 – 6 pm</td>
</tr>
<tr>
<td>9 October</td>
<td>4 – 6 pm</td>
</tr>
<tr>
<td>23 October</td>
<td>4 – 6 pm</td>
</tr>
<tr>
<td>30 October</td>
<td>4 – 6 pm</td>
</tr>
<tr>
<td>6 November</td>
<td>4 – 6 pm</td>
</tr>
<tr>
<td>13 November</td>
<td>4 – 6 pm</td>
</tr>
</tbody>
</table>

Course Schedule for Groups Meeting on Thursdays
at Dept. M, Aarhus Kommunehospital.

<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 September</td>
<td>4 – 6 pm</td>
</tr>
<tr>
<td>27 September</td>
<td>4 – 6 pm</td>
</tr>
<tr>
<td>4 October</td>
<td>4 – 6 pm</td>
</tr>
<tr>
<td>11 October</td>
<td>4 – 6 pm</td>
</tr>
<tr>
<td>25 October</td>
<td>4 – 6 pm</td>
</tr>
<tr>
<td>1 November</td>
<td>4 – 6 pm</td>
</tr>
<tr>
<td>8 November</td>
<td>4 – 6 pm</td>
</tr>
<tr>
<td>15 November</td>
<td>4 – 6 pm</td>
</tr>
</tbody>
</table>

The draw for course participation will take place at briefings at day section M (dagafsnit M) at 4-4.45 pm. on 16 August, 21 August, 28 August or 6 September. If you agree to participate in the study course, please return the enclosed note with the questionnaire letting me know which meeting you will be attending.

Refer to the brochure “Before making up your mind” for more information about your rights.

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---

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**Anonymity**

- Personal information from your questionnaire and work sheets and information concerning your blood samples is confidential and will be kept confidential throughout the study.

At the end of the study, when the results are published, I will make sure that you cannot be identified from the information published.

**You may later decide to leave the study even if you agree to participate now!**

- Participation is completely voluntary and if you choose to participate, you may withdraw from the study at any time without stating the reasons for doing so. If you withdraw from the study this will in no way affect your future care or treatment.

Yours sincerely,

Vibeke Zoffmann
Registered Nurse, MPH, PhD student
PhD publications from
Department of Nursing Science, Faculty of Health Sciences, University of Aarhus

Inger Moos:
  *Narration og identitet i interaktioner mellem plejehjemsbeboere med Alzheimers demens og plejepersonale.* 2004

Vibeke Zoffmann:
  *Guided Self-Determination. A life skills approach developed in difficult Type 1 diabetes.* 2004