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The Borderland between Care and Self-Care

BY

ANNA SARKADI



ACTA UNIVERSITATIS UPSALIENSIS
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ABSTRACT

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The aim of this thesis was to examine different approaches to support the self-care of persons with Type 2 diabetes, with special reference to practical, social, and sexual aspects of women's self-management. The methods to elucidate this comprised: evaluating a new model for diabetes patient education; designing a model to analyse the role of social networks in women's diabetes; conducting individual and focus group interviews for deeper understanding of the social and sexual aspects of diabetes; and collecting questionnaire data as a complement to the above.

The experience-based educational program led by pharmacists was found to improve participants' subjective control over diabetes and to provide important emotional support and encouragement to continue self-care. Metabolic control as measured by HbA_{1c} temporarily improved. The social network model elucidated potential mechanism leading to conflict of disease and social demands in women's diabetes. Qualitative analysis of the focus group interviews pointed to the role of guilt, shame, and social taboo in connection with the women's diabetes and sexuality.

Borderland is the metaphor I have chosen to describe the space between the traditional health care system and the everyday self-care of people with chronic disease. Using Borderland as a framework, a future model for diabetes management, anchored in our own and other's findings, is outlined and the concept of "Disease Manager Role" is introduced. The vision of a self-care support center in Borderland addresses such issues as accessibility, continuity, equitable provider-user relations, shared care plans, and strengthening social support.

Key words : Type 2 diabetes, chronic disease management, patient education, self-care, pharmacists, women, social network, intimacy, guilt and shame, female sexual dysfunction.

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To:

Robert, my love and companion

Fanny, my darling baby

Mama, Papa, and Nagymama

This doctoral thesis is based on the following five articles, which will be referred to in the text by their respective Roman numerals:

- I Sarkadi A, Rosenqvist, U. Study circles at the pharmacy – A new model for diabetes education in groups. *Patient Education and Counseling* 1999; 37:89-96
- II Sarkadi A, Rosenqvist, U. Field test of a group education program for Type 2 diabetes: Measures and predictors of success on individual and group levels. *Patient Education and Counseling* In press
- III Sarkadi A, Rosenqvist, U. Social network and role demands in women’s diabetes – A model. Submitted
- IV Sarkadi A, Rosenqvist, U. Intimacy in focus: Guilt, shame, and sexual dysfunction in women’s Type 2 diabetes. Submitted
- V Sarkadi A, Rosenqvist, U. Contradictions in the medical encounter: Female sexual dysfunction in primary care contacts. *Family Practice* In press

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The artworks used in this thesis are reproduced with the kind permission of the artists: “The Contra-bass” by Margit Artner (p. 13) and “The Violinist” (p. 53) by Judit Ekhardt. I thank both of them for their generosity.

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Swedish summary – Sammanfattning på svenska

GRÄNSLANDET MELLAN VÅRD OCH EGENVÅRD

Rollerna i vårdmötet har genomgått stora förändringar de senaste åren. Maktförhållandet mellan vårdpersonal och vårdkonsumenten har mer och mer närmat sig jämvikt. Trots det är dagens vårdstruktur inte lämpad att uppfylla kroniskt sjuka människors behov och ett helt nytt synsätt tycks vara nödvändigt.

Syftet med avhandlingen har varit att undersöka olika möjligheter att stödja personer som ämnar att ta på sig en aktiv roll i att sköta sin sjukdom med hjälp av egenvård. Praktiska, sociala och sexuella aspekter av att leva med Typ 2 diabetes som kvinna har särskilt undersökts. Metoder som användes bestod av: evaluering av en ny modell för patientutbildning i diabetes; utveckling av en modell för att studera det sociala nätverkets roll i kvinnors diabetes; genomförande av såväl individuella som fokusgruppintervjuer för att få en fördjupad förståelse av sociala och sexuella aspekter vid diabetes; och insamling av frågeformulärdata som ett komplement till ovan.

En modell av patientutbildning för Typ 2 diabetes, utanför ramen av den traditionella sjukvården, har utvärderats. Den erfarenhetsbaserade studiecirkeln ledd av farmaceuter har visat sig öka deltagarnas subjektiva kontroll över sjukdomen. Deltagarna gav också varandra stöd och uppmuntran att fortsätta egenvården. Den metaboliska kontrollen mätt med HbA_{1c} visade en övergående förbättring.

Kvinnor som har intervjuats upplevde en konflikt mellan sjukdomens krav och de sociala krav de ställts inför. Modellen av kroniskt sjuka kvinnors sociala nätverk har används för att belysa sjukdomsrelaterade aspekter av familj, yrkesarbete, den sociala miljön och sjukvården, med särskild hänsyn till möjliga grunder till rollkonflikt. Den kvalitativa analysen av fokusgruppintervjuerna visade på betydelsen av skuld, skam och sociala tabun i samband med kvinnornas diabetes och sexualitet. Brist på information samt lättåtkomliga egenvårdsartiklar, tillsammans med den skuld och skam äldre kvinnor tycks förknippa med sexualitet gjorde att dessa kvinnors sexuella problem upplevdes förbli ”osynliga”. I motsägelse till tidigare forskningsresultat och den allmänna uppfattningen, kände sig inte de intervjuade kvinnorna fria att ta upp ämnet sexuellt samliv med sina husläkare. Den motsägelse som härmed uppstår i konsultationen rörande sexuella frågor mellan en postmenopausal kvinna och hennes läkare beskrivs och analyseras.

Gränslandet är den metafor som används i denna avhandling för att benämna det föga definierade territorium som befinner sig mellan den traditionella sjukvården och kroniskt sjuka människors vardagliga egenvård. Med Gränslandet som ram beskrivs en framtidsmodell av diabetesvården, baserad på såväl våra som andras resultat. Det nymyntade konceptet ”Disease Manager Role” tillskriver individen kompetensen att fatta viktiga beslut om egna hälsorelaterade beteenden och mål för egenvården. Verksamheten i Gränslandet innehåller aspekter som främjar åtkomlighet, kontinuitet, ökad jämlikhet i maktrelationen mellan vårdkonsult och vårdkonsument och förstärker det sociala stödet.

PROLOGUE

I have chosen a somewhat unusual way to present my thesis and in the passages that follow I will provide a short orientation to familiar the reader with the thesis's structure. There are seven chapters: the first gives an introduction, outline, and disposition while the seventh chapter hosts the general discussion and conclusions. The intermediate chapters are based on the five articles that make up this thesis. An exception is Chapter 5. in which the complete analysis of the material for IV and V is presented. *Theoretical perspectives*, *Results*, and *Methodological considerations* construct Chapters 2-6.

The sections on *Theoretical perspectives* serve to increase the reader's understanding of the theories used, investigate and develop different concepts, and place the research into its proper context. To provide a broader basis for discussion I present theories from the fields of sociology, psychology, philosophy of science, and feminism, all of which in some manner relate to the article. I see strength in a truly interdisciplinary approach. Theories related to qualitative methods have shown me that knowledge is not equal to descriptions in textbooks. I believe it is important to have broadened my view by reading works from numerous disciplines and aiming to understand the way others make sense of reality.

Certainly comprising socialization to a traditional value system, my medical background has nonetheless taught me that several 'truths' may exist, depending on time and cultural context, as well as the physicians, patients, and diseases involved. Therefore, I have been skeptical to authors that advocate their truths as the unrivaled viewpoint. From this perspective, I have sought to give a picture of the various views concerning issues discussed in the chapters of this thesis.

In the *Result* sections, I describe findings from the original research. The summary of a thesis should be able to be read on its own and hopefully enough results have been cited to obtain understanding of the findings. When writing the *Result* sections, I have been dealing with the (still unsolved) dilemma of which tense to use: *I* or *we*, singular or plural. Research on a Ph.D. level is not performed "in singular," it is *we*, or initially even "my tutor and I" who stand for the results. However, as time advances, ideas develop and new subprojects are initiated. So, gradually the one responsible for the results – good or bad – is "*I*." Therefore, in studies from earlier dates and the chapters dealing with them I tend to use "*we*," whereas in later studies and when describing ideas considered my own I preferred using the singular pronoun "*I*." The passive voice is, of course, sometimes a solution, but it does not resolve my dilemma of singulars and plurals.

The truth-value of a study is contingent on the methods used. All methods have their flaws and the task of the researcher is not to eliminate these, but to be cognizant of their existence and consider them when drawing conclusions. The objective of the *Methodological considerations* sections is to describe the way results might have been influenced by properties of the methods employed. In several chapters, I also discuss the implications of using certain theoretical frameworks and methods.

The above way of presenting my thesis seemed logical. I chose the form to fulfill a function, namely, to describe the process of becoming a Ph.D., which in my view is learning to think on your own using existing theories, methods, and research results in a comprehensive fashion.

I now wish the reader a pleasant journey across theories, results, and reflections and hope that I have succeeded in making this thesis both scientifically correct and easy to read. Most of all, I hope that the reader will find some new thoughts to contemplate.

Acknowledgments

Reading a thesis often begins with careful examination of the Acknowledgments. It is, in fact, one of the most exciting parts. Why is that?

Those who have been of help are curious whether their contribution is remembered. Writing a thesis today is, indeed, teamwork. The polyhistor of old times are gone and the linguistic, methodological, and technical aspects of a thesis need the knowledge and experience of several people. Theoretical guidance and practical aid are also invincible. Hence, I am deeply grateful to:

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Abbreviations and Definitions

ANOVA – Analysis of variance statistical method

BMI – Body Mass Index, calculated as body weight (kg)/height² (m). Normal range ~20-25

Etiology – The study of causality. Explains the origin of the phenomenon under study

Glucose – ‘Grape-sugar’; a ubiquitous sugar compound and important energy source for the human body, especially the brain

Glycemic control – Near-normal long-term blood glucose levels as measured by HbA_{1c}

GP – General practitioner, also called family physician

HbA_{1c} – Glycated hemoglobin, a measure of blood glucose levels 6-8 weeks before sampling. Normal range: 3.5-5.3% in our reference laboratory

Insulin – Hormone produced by pancreas β -cells to help glucose enter the cells from the blood

Macrovascular – Affecting large vessels

Microvascular – Affecting small vessels

Morbidity – Disease rate

Mortality – Death rate

Neuropathy – Nerve disease

Odds ratio – Statistical odds of a certain event where 1 describes no effect of the explanatory variable on the examined phenomenon. Values < 1 describe decreased risk whereas values > 1 mean higher risk

Prevalence – Presence of a disease/condition in the population

Sexual dysfunction – Objectively demonstrable disturbances in different phases of the sexual response cycle

Sexual problems or disturbances – Subjective experience of sexual malfunctioning

The IDF – The International Diabetes Federation

UKPDS – United Kingdom Prospective Diabetes Study, a large longitudinal study of Type 2 diabetes in the UK

WHO – World Health Organization

PART ONE
DIABETES IN BORDERLAND



Chapter 1

THE BORDERLAND BETWEEN CARE AND SELF-CARE

1.1 INTRODUCTION

As soon as I enter a hospital, I need to take a deep breath. This is the palace of Disease, Cure, Suffering, Birth, and Death. This is the Land of Medicine. An actor, a janitor, a teacher enters here and becomes The Patient. The trolls in white, running in the corridors are Nurses, Doctors, or Health Care Professionals, to be more fancy. The rules are strict, the roles given, and the boundaries of steel. This is where the Medical Encounter takes place. Good or bad, democratic or hierarchic, it is short. Fifteen minutes compared with the 1,440 of a single day.

I ring the bell on Sarah's door. She lets me in and invites me to the kitchen table. She just put on a cup of coffee and its smell fills the house. This is the Land of Home, where Diabetes and Sarah live together with Sarah's husband and the old cat, Tom. I don't take sugar, Tom gets one of Sarah's - a routine that has made Tom even fatter, but Sarah is in better control of her blood sugar. Before tasting her sandwich, Sarah takes a dose of insulin. She knows about how much: some milk in the coffee, butter, ham and cheese in the sandwich, and a planned half-hour walk afterwards. It's Routine, Everyday Life to her, although she has not had Diabetes for such a long time. When we come back from our walk, she checks her Blood Sugar. The number 6.8 on the display of the palm-sized machine tells her some things: she got the insulin dose right (not like the other day when she nearly fainted), the walk has not been more demanding than planned, and her blood sugar is in a range she thinks is acceptable. She starts baking a pie while we talk. Not so good for the Sugar, but the grandchildren love it. She'll have a bite, too. It's so unpleasant to just sit there when the others eat.

Between the hospital corridors and Sarah's kitchen, there is a space - Borderland. The Land of Medicine is alienating, frightening, or simply, Other and thus non-relevant for Sarah; the Land of Home is unreachable and often Hard-to-Understand for the Doctor. Borderland is a neutral land where Sarah and her Medical Advisor could meet to discuss life with diabetes without value judgments from the Doctor (non-compliant, BAD patient) and signs of displeasure from Sarah's husband (salad is not food). Borderland is there for everyone to explore. I attempt to walk it with open eyes and invite the reader to join in.

1.2 AIMS

Borderland is the metaphor I use as a tool to elaborate a model of future diabetes care in this thesis. However, our work was guided by certain general and specific aims throughout the research process.

General aim: To examine different approaches to systematically support the self-care of persons with Type 2 diabetes, including practical, social, and sexual aspects of self-management.

Specific aims:

1. To evaluate a feasibility study of the pharmacist-led *study circle* group educational program for persons with Type 2 diabetes.
2. To describe the effect of demographic variables on success in the study circle educational program.
3. To design a model to enhance our understanding of the role of culture and social network in women's diabetes.
4. To shed some light on the effects of diabetes on intimacy, as experienced by a purposeful sample of middle-aged and older women.
5. To analyze and understand those results in our study that are related to women's unwillingness to discuss sexual issues with their general practitioners.
6. To summarize and immerse the present results and those of others into a future model of diabetes care.

1.3 CENTRAL CONCEPTS

In this section, I will discuss three concepts that have been central to the work presented in this thesis: patient empowerment, self-care, and the metaphor of Borderland. I will draw upon the existing evidence on how successful care for people with a chronic disease should be designed and carried out, as well as philosophical and ethical considerations of empowerment and self-care.

Patient Empowerment

Each time persons living with diabetes are asked what they really want in terms of care, they refer to the same three desires: to be listened to, to be acknowledged as competent decision-

makers of their health-related behavior, and to receive long-term support (1-3).

Figure 1. A consumer view on what is needed from health professionals to support self-care effectively. Illustration by Panni Fridrich ©



To emphasize my sincere respect for the people with diabetes, I will deliberately avoid using the term 'patient' when referring to persons with diabetes in a health care setting and the associated term 'compliance' when referring to their chosen self-care behaviors. (Although I dislike the word 'patient', in lack of a better alternative and to avoid misinterpretations, I will use it in citations, expressions such as 'patient education' or 'patient empowerment,' and when referring to consumers of health care in general.) These semantics reflect a whole value system and attitude, the applicability of which has been questioned in chronic disease management (4). "While being a patient may be an important aspect of being ill, it is by no means the only one nor necessarily the most important" (5)¹.

In his textbook for physicians from 1947, the Austrian professor of internal medicine, Jagic, wrote: "In all cases of diabetes, hospital observation every or every other week is recommended, in order to aid diet adjustment with daily blood and urine sugar controls," p. 175 (6). Today, persons with diabetes are expected to carry out the bulk of diabetes therapy alone. Young or old, well-educated or not, people with diabetes have to measure their blood glucose (7), administer insulin or oral agents to themselves, and choose their food according to certain principles (8).

Since Jagic wrote his book, roles in the medical encounter between sick persons and their caregivers have changed drastically (9). These changes have particularly affected the

patient-doctor relationship in chronic diseases, where contacts are often durable and decisions both influence and are influenced by the patient's everyday life. As a hallmark of change, e.g., the term "diabetic" is no longer acceptable for use as a noun (10).

Nonetheless, health care professionals are in a power position (11-13) in relation to the help-seeking person. Thus, if not handled with care, the power to help may turn into power to oppress individuals (1) by implying to them their own guilt in having developed a certain disease and labeling them with value judgments, such as "non-compliant" or "denying" (14). William-Olsson goes so far as to suggest that health care personnel "needs patients to give vent to their contempt, to despise those who (...) do not obey," p. 145 (1).

Since the late 1980s, patient empowerment has increasingly become a philosophy of diabetes educators at a number of training centers in the USA (15). The empowerment approach in diabetes management assumes three principles (15):

1. Persons with diabetes are de facto their own primary health care providers;
2. Persons with diabetes have the right to be primary decision makers regarding their own diabetes care considering that they experience the consequences of both having and treating diabetes; and
3. The goal of education is to help persons with diabetes make informed choices and achieve self-selected goals regarding diabetes care.

An additional, underlying assumption is that knowledge, skills, and sense of personal autonomy will help individuals "take charge of their own diabetes" (15). Some of the theories concerned with the linkage between educational input and metabolic outcome, i.e. whether education and empowerment automatically leads to superior diabetes control, will be further discussed in Chapter 3. For now it is sufficient to state that the current view guiding most chronic disease educational efforts is that empowerment and enhanced self-efficacy will indeed produce better long-term results (16, 17).

From the perspective of the person with diabetes, more equity in power relations and a greater involvement in the medical consultation, as advocated by the patient-empowerment movements, can be both emancipating and constraining at once. With greater rights go greater responsibility – which individuals might or might not be ready to assume – implying a moral obligation to survey one's body and to control its size and desires. Moreover, it is suggested that empowerment would be class-biased. People of higher social class may,

¹ For articles published in international journals, only the range of page numbers is given

therefore, feel “more on equal footing with doctors” and “more empowered and qualified than people of low social class to evaluate the services of the doctor and to change to another if they are displeased,” p. 110 (11). Thus, although empowerment seems to have overtly positive attributes, these potentially negative aspects also have to be considered.

The roles patients and doctors are expected to play in today’s medical encounters are results of a changing society, one in which traditional hierarchic systems are increasingly discredited and the individual patient’s rights and autonomy are underlined. The proposition from 1998 for revision of the Health and Medical Services Act in Sweden certainly reflects the new trends and expectations considering health care systems in Western society (18). The main intention of this proposition was to strengthen the patient’s position vis-à-vis the health care system and physicians.

According to the law modification that followed, patients should have gained increased rights to more and better information, to obtain a second opinion, and to make informed choices on therapy in case of severe, life-threatening disease (19). However, the report that the proposition and later the law modification was based on received criticism because it “failed to acknowledge patients’ capability to make their own, competent decisions [about health-related issues]” (20). Representatives of a diabetes patient organization were particularly disturbed by and debated the fact that the right to second opinion only applied in cases of severe diseases with especially short life expectancy (20).

***“I keep six honest
serving men
They taught me all I
knew:
Their names are What
and
Why and When
And How and Where and
Who.”***

Rudyard Kipling
Quoted in: Patton, 1997 (43)

CARE FOR THE CHRONICALLY ILL probably needs a new framework for discussion. The above example illustrates the difficulties of formulating and implementing new intentions without changing old frameworks. The issue of ‘second opinion’, e.g., is dealt with in terms of acute or life-threatening illness, whereas the system did not seem to be ready to cope with the potentially greater autonomy needs of persons with a chronic disease. Concerns and needs of the latter

therefore probably need a new framework for discussion. I will make use of Kipling’s aphorism in an attempt to raise some of the questions I believe to draw on this new approach. The chapters touching on these issues are indicated in parentheses.

What is the goal of care for the chronically ill (Chapters 1 & 7)? *How* should this be achieved (Chapters 1,2,3 & 7)? *Why* are education, empowerment and a change of attitudes important (Chapters 1,3 & 5)? *Who* should control diabetes and whose diabetes is it, really (Chapters 3,4 & 5)? *When* will we be ready for a paradigm-shift (Chapters 5,6 & 7)? *Where* should we start (Chapters 3,4,5,6 & 7)?

Based on the analysis of available randomized controlled trials on systematic diabetes management programs, Wagner and co-workers have identified certain features that should be included in good chronic illness care (4). These features include the following:

1. Use of explicit plans and protocols based on shared care plans;
2. A continuum of self-management training and active, sustained follow-up and support services;
3. Ready access to necessary expertise; and
4. Delegation of educational, informative, and practical planning responsibilities to non-physician health care staff.

Thus, there is high-quality evidence to outline the means of promising strategies in diabetes care. The above guidelines are considered in Chapter 7 where I describe a possible future model for diabetes care – in Borderland.

Self-care

Educational programs that actively support self-care (21) and the establishment and activities of self-help groups (22, 23) as well as effective screening programs to prevent diabetic complications (24) have been implicated as important strategies in dealing with Type 2 diabetes. Without the effective participation of persons with diabetes themselves, however, all management strategies are bound to fail: it is increasingly recognized that the major resource for diabetes care is the people themselves (15, 25-27). Health educators' role, then, is "to help expedite the process of knowledge, skill, and technology transfer from the professional to the lay component of the health care system" (27). In the following, I therefore wish to consider the most essential component of diabetes management, namely, *self-care*.

Self-care can be defined as both a rather broad and a narrower concept. The wider concept includes "the range of behavior undertaken by individuals to promote or restore

their health” (28), whereas the more specific meaning comprises self-treatment of a chronic disease with the support of health professionals.

The critique of Parsons’ sick role model (29) for its “professional bias” has called attention to the “unofficial” health care activities of lay people (the broader concept of self-care) that had received little attention since the emergence of modern health care systems. The overemphasis of medical professionals and the technical resources associated with medical practice have been argued to belittle not only the individual’s own health practices, but also “the importance of lay significant others for the patient’s recovery” (30). It has been increasingly recognized that the family is the core for most of the health care, where decisions on definition of illness, seeking help, and evaluating care take place: “knowledge about the extent of self-treatment, [and] the impact of family on care (...) can be sobering,” p. 59 (14). Women’s roles in the factual primary care, taking place in the homes of people, has also attracted attention (31); the implications of this care on women’s health is further discussed in Chapter 4.

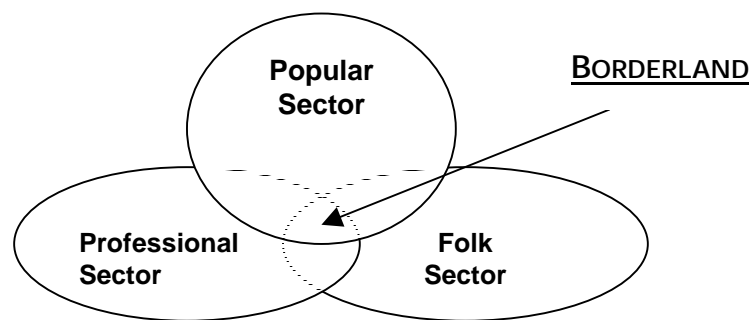
Self-care in chronic disease “satisfies the need for identity, fulfillment, and optimizing the human potential as a constructive social resource” (27). It is this philosophy and definition of self-care that is used in this thesis, as it views individuals as important resources in health care who can make their own choices on whether to exert certain health-related behaviors. “People who may perceive their role as limited in *curative* disease, in contrast, see their role in *carative* disease management as practical and appropriate” (27). To paraphrase Levin, lay persons who have been socialized to accept the totality of medical authority in case of acute or “usual” illness become experts of their own bodies through self-care in chronic illness.

Defining self-care in terms of knowledge and experience also has clear implications for the power relations within the medical encounter: “effective listening, encouragement, and guidance” are needed of health professionals in sharp contrast to “administration of treatments to passive patients” (28). The way self-care, in turn, is or is not performed may differ substantially among individuals; it is this personalized character of chosen health-behavior that the term self-care (self-decided, administered, and censured care) recognizes. Thus, in this thesis the **definition of self-care is conscious, chronic disease-related health behaviors undertaken by persons who manage their habitual conditions with more or less regular support from professional health care personnel.**

Borderland

In the Introduction, I have defined Borderland as the space between Sarah’s home and the hospital corridors. Although the designation “Borderland” is new, the concept and the will to bridge the gap between the professional and personal sphere of health care is not. Agencies acting in **Borderland, defined as the space between official health care and the self-care of people**, have existed ever since the rise of modern health service systems. Kleinmann described three overlapping health systems: the bio-medically oriented professional sector, the folk sector, i.e. different types of traditional medicine and folk healers, and the popular sector, including individual, family, social network, and community-based care (14).

Figure 2. Schematic representation of the place of metaphoric Borderland in Kleinmann’s model of Local Health Systems (14)



Kleinmann, of course, did not mention Borderland, but in Figure 2., based on Kleinmann’s model of Local Health Systems, I tried to indicate where Borderland could be placed in his model. Although Borderland is not “reserved” for chronic diseases, there are examples of this aspect of Borderland care that I will mention in the paragraphs that follow.

Self-help clubs and mutual aid groups had increasingly appeared in the USA during the 1970s (22). Importantly, these were not “merely filling a vacuum of professional services (...) [but constituted] a preferred strategy in health, used in conjunction with professional care, but offering benefits which may be unique to the situation of self service” (27).

Other examples are clubs that can also serve the purpose of supporting self-care. On Cuba, a five-year program named Continuing Interactive Education was introduced to deal with the daily, practical self-care needs of persons with Type 2 diabetes (23). The program was organized in a social club setting and resulted in significant increases of knowledge and skills on disease management and a reduction in participants’ body weight and the required

daily dosage of hypoglycemic agents. Other ways to support self-care include courses in diabetic cuisine, as those provided by the Swedish Diabetes Association, and training facilities with possibilities for socializing for cardiac rehabilitation (32).

In Oslo, Norway, a “Management Center” for chronic diseases was established (33). The Center is characterized by the view of users, i.e. persons with chronic diseases as resources for their own care. The main goals of the Management Center are to provide a forum for information exchange and a place for people with different conditions to meet and to organize education for chronically ill persons and their relatives (e.g., “sibling groups” for children who have a brother or sister with epilepsy).

In summary, there are a number of existing and well-functioning agencies in Borderland. These agencies fill a need of social anchorage (22) and long-term support for self-care. However, clubs and self-help organizations inevitably select their members and the degree to which medical management is part of these concepts differs widely. The idea of Borderland care for Type 2 diabetes presented in this thesis aims to offer self-care support and anchorage to all persons with the condition and includes medical management within the holistic concept of care. A paradigm shift is proposed from the framework of diabetes care today to that of Borderland.

1.4 THE RESEARCH PROCESS

My journey to Borderland began with my becoming responsible for evaluating the pilot study of a diabetes educational program that was based outside the framework of traditional health care. Pharmacists were trained to become group leaders for persons with Type 2 diabetes and conducted group meetings that took place at pharmacies or conference rooms.

The results of the pilot study indicated that the study circle program was feasible for educating persons with Type 2 diabetes (I). However, looking at the participants’ HbA_{1c} values², a measure of blood glucose during a period of 6-8 weeks, one question kept entering our minds. Why was there a relapse leading back to baseline levels of HbA_{1c}, following a significant decrease of HbA_{1c} values during the first six months of participation? In an effort to answer this question, we began our inquiry by analyzing each group and

² See Abbreviations and Definitions and Chapter 2 for further explanation of the term

realized that some individuals did succeed; i.e. they did not show a relapse. Who, then, were these persons? This question led us into the second phase of our study.

With an increase in the number of localities and with more people entering the program, we soon had access to a growing number of observations. This circumstance allowed us to perform several analyses to elucidate factors that influenced metabolic success in the study circle. We found that high initial HbA_{1c} led to greater decrease in HbA_{1c} values, whereas being overweight and feelings of loneliness in some treatment groups negatively affected outcomes (II). The differential effect of loneliness, resulting in better diabetes control for diet-treated persons, indicated interaction between diet self-care and socializing associated with meals. Thus, we started out with a search for individual demographic factors that would determine success and were left with the conclusion that, although individual measures of body size and disease control play a role, social aspects, such as feelings of loneliness, are likewise important and hence need to be taken into account.

The next stage in our project therefore came to involve diabetes-related aspects of the individual's social network. Letting the project take this new, unforeseen turn was a conscious choice, although it meant abandoning the original plans³. Our decision was based on the assumption that in order to provide comprehensive support for diabetes self-care in the study circles or otherwise, a better understanding of "diabetes-related personal conditions" of individuals was required. We conducted a *Medline/Sociological Abstracts* search using the key words "chronic disease" and "social support/network/surrounding" and found ample literature on the role of social support in coping with illness, especially about male cardiac disease. When we used the search words "women" and "chronic disease/illness," most studies that surfaced pertained to spouses of chronically ill men and mothers taking care of their disabled children, or ill, elderly relatives.

This apparent scarcity of literature on women's chronic diseases led us to focus on women with diabetes. Additionally, in our first interviews for evaluation of the study circles the women participants spontaneously commented on 'conflicts' they had experienced. Descriptions summarized under the "*Role Conflict in Diabetes*" category in the qualitative analysis included women's lack of 'own' time for exercise or having to prepare different meals for themselves and the family.

³ The originally planned randomized control trial was also started afterward and will be concluded March 2001.

When we finally tracked down relevant literature using the “Related Articles” function in Medline, the *Science Citations Index*[®], and references contained in the articles, we found that earlier results had pointed to some specific difficulties women experience in relation to coping with a chronic disease. To answer our research question on the “diabetes-related personal network conditions” of women and to provide a basis for systematic analysis of findings, we used network theory as our basic framework. (III).

Qualitative studies I had read during the literature review cited women commenting the effects of chronic disease on their femininity and intimacy. I remember well the words that woke my interest for the next field of investigation: a woman telling the interviewer about her disturbing vaginal dryness and lowered sexual desire since her diabetes diagnosis.

“I think – if there’s something with the men, could there be something with the women? But there is nothing on it – you never see anything on it. The doctor never said anything when I mentioned it, so I figured it must not have anything to do with the diabetes – it’s just me” [in LeMone, 1996 (34)].

Subsequently, my questions that were to be answered in a series of focus group interviews and a preceding literature survey narrowed down to the following. How common is female sexual dysfunction in diabetes? Do women perceive diabetes as affecting their intimacy? Do they relate eventual sexual problems to their diabetes? Do they express the desire to receive medical attention for their sexual disturbances?

The women were surprisingly candid during the focus group interviews and talked relaxed about issues considered “sensitive,” such as sex and intimacy. On the other hand, it was astonishing to hear the way women perceived their sexual dysfunction to be rendered invisible (IV). Social taboo, gender bias of sexual health care, lack of remedies, and the guilt and shame this generation of women associated with sexuality seemed to be the contributing factors, according to the resulting categories of qualitative analysis.

Participants did not feel comfortable discussing sexual disturbances with their general practitioners (GPs). Other studies, conducted with healthy participants, found that women would talk to their family physicians about sexual problems when asked, although they might not volunteer such information (35-37). This contradiction between findings in the interviews and those in the literature prompted the final field of investigation (V). I reexamined the qualitative analysis category of “Sex issues in physician contacts” to provide a more detailed understanding and addressed the following questions in the discussion. Who

provides/should provide care when it comes to female sexual dysfunction in diabetes? Is sexual dysfunction a concern of women only or should health care address this issue? The conclusion of the study is that, when it comes to managing sexual dysfunction, this generation of women could possibly benefit more from services offered by patient or women's organizations equipped to provide basic sexual counseling/information than from traditional medical consultations where the issue might not even be mentioned. Probably more research is needed to elucidate with whom different generations of women prefer to discuss sexual issues, or, to continue the metaphor, walk the Borderland.

Thus, and perhaps not surprisingly, the journey ends where it began – in Borderland. In Chapter 7, I revisit Borderland to formulate the practical and theoretical implications of this thesis and draw upon a possible future model for diabetes care.

1.5 REFLECTIONS ON THE RESEARCH

“The context of discovery”

“The myth about the neutral, apolitical man of science is no longer acceptable. Research is a social and political activity that has implications for our collective lives,” p. 183 (38). Scientific observations are always impregnated by theory; they are influenced by the paradigm within which they are made (39). The same phenomenon/empiric reality can be described in different ways by researchers with differing professional socialization. According to social constructionist theory, truth is “the product of power relations, and as such, is never neutral, but always acting in the interests of someone,” p. 11 (11). “The context of discovery” as an expression of the above was coined by Hansson (40).

The challenge of working in a field like social medicine as “the context of discovery” is that it is a meeting place for two fundamentally different research traditions: the predominantly prescribing or problem-solving approach of medicine and the descriptive and explanatory ambition of social science. Results in social science often comprise analyses, comprehensive models, and theories. Results in medicine are expected to yield concrete answers and practical advice.

“Social medicine has predominantly been a science with ambitions to prescribe. The aim has been to find practicable solutions to medical problems with a social etiology” (41).

In this thesis, I wandered on the border of two fields of science. The metaphor of Borderland felt as suitable for my place as a researcher as for the phenomena and their inherent problems I describe, try to understand, and yes indeed, propose solutions to. I grew to understand that the common denominator of the new projects I introduced to the research process was the realization that social values, medical knowledge, definition of illness, and gender roles are culturally constructed. Social constructionist theory was long before me in describing this, but the notion that this state of affairs had very personal implications on the research process and findings was novel for me. It was, e.g., no longer enough to conclude that the educational program worked well. I also had to consider the rights and wrongs of health education, the potential class-bias of the empowerment concept, and cultural as well as gender aspects of living with a chronic disease.

It is a true experiment of thought to try to figure out what I might have seen, e.g., in the material from the focus group interviews on intimacy with women who had Type 2 diabetes if I had a background in pedagogy, behavioral science, economy, theology, or philosophy. First, the probes in the interview would probably have differed. I might have concentrated on the social and spiritual aspects of sexuality, the “aging relationship” and its psychosocial and behavioral aspects, the role of sex and sexuality in women’s lives, or the socioeconomic implications of sexual functioning. The analysis might have involved less “problems” to be solved and more of the social, economic, and religious hindrances or resources women had. Health economics of sexual aid use or the role of priests and population education in sexual care might have been considered in my discussion.

***"Through seeking we may
learn
and know things better.
But as for certain truth,
no man
has known it. (...)
For all is but a woven web
of guesses."***

However, whatever conclusions I have made during this hypothetical experiment are still influenced by my medical socialization. Accepting these flaws of *scientific facts* is probably a good start when considering research results in a greater context. For me, this translates into the notion that the theories and people, as well as the numerical questionnaire data and their analyses I have worked with, are influenced by

my choices as a professional and private person. Consequently, my results reflect the way knowledge is constructed at the turn of the 21st century by a young mother, wife, and

medical student doing research at a Western public health department with almost only males in key positions and with almost only females as peers and discussion partners.

Using Qualitative Methods. Time to Abandon the Position of Defense?

In the past two decades, qualitative methods have increasingly gained legitimacy in the field of health sciences. However, those using the method often adopt a defensive attitude and provide extensive motivation as to why these methods have been used instead of the traditional quantitative ones. The sheer fact of having employed qualitative methods is implied to threaten validity, reliability, and objectivity, properties that are assumed inherent in conventional positivistic research (42).

Within the field of evaluation, the qualitative-quantitative debate “has run out of intellectual steam and is now relegated to comedy on the Internet,” p. 266 (43). The field of medicine, however, (nursing science excluded) has been especially unwilling to accept results of qualitative studies as valid (44). Expressions, such as ‘soft data,’ have been coined (39), referring to the uncertain and variable nature of human experience as a data source, as compared to the ‘hard data’ of traditional, *objective* research.

The dialectic of ‘soft’ and ‘hard’ data probably has its origin in the gender assumptions of valid knowledge: women (the bulk of the researchers using qualitative methods) representative of intuition and sensitivity (45) versus men (dominating in the labs and editorial boards) representative of rationality and reason (45). The ‘soft’ versus ‘hard’ dialectic certainly reflects the value judgments associated with the results of research based on such data and the researcher involved. Not to mention the degrading overtone, labeling the lived experience of human subjects as ‘soft,’ and hence, unreliable, as opposed to the ‘hard’ and reliable laboratory or statistical data.

The quantitative-qualitative debate has been so effective in creating dialectics that comparative and defensive overtones have tended to characterize discussions advocating the use of qualitative methods in medical research (46-48). As a result of the perceived need for self-surveillance to prove ‘good enough’ in the comparison with quantitative studies, researchers in the field of qualitative inquiry often state that ‘strict’ criteria for scientific rigidity should be expected of researchers using qualitative methods (48-51). Whoever states that a laboratory researcher should learn to use a pipette properly before preparing cell cultures, and that basic statistical knowledge is a prerequisite of ascertaining probabilities? Is

it not self-evident that researchers do their absolute best to produce sound knowledge, as they do not unduly claim results others have produced and gain the informed consent of participants, as stated in the Declaration of Helsinki, 1975? I agree with many researchers working at public health or other social-medical departments. The guiding principle for choosing methods should be *method after purpose*.

“We should not decide in advance which research method we are going to use, but choose the one that is most relevant for our purpose. It is therefore important for researchers within medicine to have a wide enough methodological competence that permits an optimal choice,” p. 35 (51).

However, when combining these methods, quantitative data should not be used only to underpin the results of the qualitative component, or to ensure acceptance by the world of medicine: rather, true completion should be the goal (52).

USING QUALITATIVE METHODS has certain implications on the researcher’s attitude. If we want people to share their innermost, private, and maybe shameful thoughts with them, there is a need for investing ‘emotional risk-capital’ in the participant: “no intimacy without reciprocity” (53). According to Oakley, this includes answering questions participants have, accepting hospitality offered, and maybe even helping with housework or whatever is on the agenda of the interviewed woman (53). There is a sensitive balance to be achieved between exploiting the research subjects as mechanical sources of data and “going native” (48), i.e. to become so involved in the lives of persons interviewed that the necessary distance to the resulting material no longer exists.

Oakley goes on to state that the interviewer is “an instrument for promoting a sociology for women,” p. 48 (53), which I personally do not feel is the most fruitful attitude to have because the interview, after all, is a way of gaining information and increasing understanding. What this information results in on the social-political level is the question of advocacy and not a scientific result (see Chapter 6). On the other hand, it seems only fair that the “interviewing process [should] offer some personal satisfaction,” p. 49 to those interviewed (53). The means of how this should be achieved are a matter of taste, temper, and professional and theoretical orientation. One should certainly aim to give a clear description about these personal participant-interviewer interactions, as well as how they might have affected the results.

Chapter 2

DIABETES – FROM DEADLY DISEASE TO SELF-MANAGED CHRONIC HEALTH PROBLEM

2.1 THEORETICAL PERSPECTIVES

Diabetes Mellitus

Diabetes mellitus includes a group of diseases characterized by chronically elevated blood glucose levels because of decreased insulin producing capacity or because of decreased ability to use available insulin. The metabolic and pathologic consequences of these diseases are rather similar, which accounts for why the somewhat different conditions are commonly grouped under one heading. Type 1 (insulin-dependent diabetes) and Type 2 (non-insulin dependent) diabetes are the recommended terms for the most common forms of the disease (54), the latter accounting for 85-90% of all diabetes.

Type 1 diabetes is more likely to develop in childhood or early adulthood, whereas Type 2 diabetes usually emerges in middle or old age, reaching a prevalence of up to 10% among those over 70 years of age (54). In accordance with these findings, Type 2 diabetes is often thought of as a disease of the elderly. However, according to 1998 statistics, 23% of diabetes outpatients in Sweden (97% of these have Type 2 diabetes) were between 30 and 59 years old and 10% had their onset of diabetes at a mean age of 43 years (55).

FROM A HISTORICAL PERSPECTIVE, it took only about 70 years for diabetes, known as a deadly disease for almost 2000 years, to become a self-managed chronic health problem. Although symptoms of diabetes had been known for several thousand years, its diagnosis was scientifically first described by the British physician Thomas Willis in the 17th century (56). It was his advice that physicians should taste the patient's urine to determine whether it tasted "like honey".

The names of Langerhans, describing the pancreatic islets, and Kussmaul, giving his name to the typical breathing of diabetic coma, have been carved into the minds of all medical students since 1869 when these scientists made their discoveries (57). Twenty years later, in 1889, the heart of the diabetes problem was found to be the pancreas: removing it from dogs led to their urine becoming sweet and to their death within a couple of weeks. Insulin (from the Latin word for island – insula) was first purified from dog pancreas by the

famous research duet, Banting and Best in 1921. Luckily, neither of them died of insulin coma or allergic reaction when they gave each other cow insulin to test its safety for human use. Human insulin was first synthesized in 1964.

While researchers were busy identifying the amino acids of insulin and creating animal models of diabetes, clinicians developed diet and treatment regimens for their patients. Noorden's rye diet and Falta's flour-fruit diet are some examples (58) that seem both inappropriate and unnecessarily meticulous today. Fasting days were recommended with strict bed rest: patients were allowed to drink weak bullion, watery brandy (sic!), coffee, and lemonade (58). Fat was considered of benefit and Noorden recommended his patients to eat any one of 300 grams of meat, 4 eggs, 50 grams of cheese, or 1/3 liter of cream per day for certain periods of time. High intestinal lavage, as well as unilateral removal of the adrenals, was applied as therapeutic measures. Although these treatment strategies are only of historic interest today, it is important to remember our own place in history inasmuch as there is no guarantee that, e.g., our more liberal attitudes to diet and transplantation efforts in diabetes will not be considered largely irrelevant in the future.

PREVALENCE OF DIABETES is dependent on diagnostic criteria and geographic location. In 1998, a WHO consultation group recommended that fasting blood glucose values required for diabetes diagnosis should be lowered to 6.1 mmol/l (from 6.7 mmol/l), as measured in whole blood (59). The working group also addressed the problem of estimating the prevalence of diabetes because of high rates of undiagnosed diabetes in the general population (2-3%), which is thought to precede clinical diagnosis with several years (60). Therefore, the category of impaired fasting glycemia ($5.6\% \leq \text{HbA}_{1c} \leq 6.1\%$), of which oral glucose tolerance test should reveal overt diabetes, was introduced (59).

Independent of new diagnostic criteria, there are already differences in the prevalence of diagnosed diabetes within Western societies, plausibly because of differences in lifestyle and longevity as well as screening routines. As defined by earlier WHO criteria (i.e., fasting blood glucose >6.7 mmol/l), diagnosis of diabetes was found to occur in 5.1-6% of the general population in the USA (61) and 3-4.3% (54, 62) in Sweden. This naturally has implications on the way national strategies for diabetes management and education should be formulated.

Diabetes is a public health concern in most Western countries (63) and is increasingly becoming a concern in developing countries (64). New criteria will only to some extent

account for the estimated doubling of diabetes prevalence in the world until 2010: a situation is largely due to widespread obesity and sedentary lifestyles, as well as younger age at diagnosis and longer survival (64).

THE PRIME GOAL OF DIABETES THERAPY is to maintain blood glucose to near normal levels by performing self-care, including daily blood glucose tests and modifying medication intake, diet, and exercise, accordingly (7). If high levels of blood glucose are carefully avoided, long-term complications of Type 2 diabetes (65, 66) and mortality (62) can be prevented.

The most common measure for diabetes control is the glycosylated hemoglobin value (HbA_{1c}), which reflects mean blood glucose levels of 24-100 days (mean 6-8 weeks) before blood sampling (67). The European Diabetes Policy Group working under The International Diabetes Federation (IDF) recommends that the treatment goal for HbA_{1c} should be $\leq 6.5\%$ in order to lower the overall risk of complications (68). The Swedish National Board of Health and Welfare has the same target value for glycemic control in their therapy guidelines for diabetes (54).

THERAPEUTIC EFFORTS to manage diabetes have changed dramatically since the 1950s. Diet has always been one of the most important measures to obtain metabolic control and treatment goals. However, major changes in the attitude towards diet therapy in diabetes have taken place in the past 10-15 years. Instead of complicated and restrictive regimens, persons with diabetes are counseled to eat a balanced, ordinary, and generally healthy diet. The chief goal for diet recommendations in Type 2 diabetes is most often losing weight. This is to be achieved by following three principles related to diet (69):

- Reducing fat to $\leq 30\%$ of food intake, especially the amount of saturated fats.
- Restricting the amount of sugar, most importantly between meals (but allowing limited amounts during meals).
- Increasing the consumption of carbohydrate products, preferably those rich in fibers and having a low glycemic index (70).

Principally, eating should be as pleasurable in diabetes as it might be otherwise without unnecessary restrictions (69).

The United Kingdom Prospective Diabetes Study (UKPDS) was the largest study ever undertaken in the treatment and outcomes of Type 2 diabetes, with 5,102 participants and a

median follow-up of 10 years (71). Subjects were randomized to “intensive” or “conventional” treatment. “Intensive treatment” with insulin, metformin (in the obese), or sulphonylureas was shown to improve microvascular morbidity, but had no significant effect on mortality. To the disappointment of the investigators, HbA_{1c} only differed by 0.9% between the two groups. The effect of glycemic control on complications had no threshold, however: any decrease in HbA_{1c} was associated with better outcomes. Tight control of blood pressure (<140/80 Hgmm) was instead shown to be extremely important in Type 2 diabetes, preventing both microvascular and macrovascular complications as well as decreasing mortality (72).

From prospective studies, such as the UKPDS, it becomes evident that diabetes has a progressive course in which the possibility of maintaining good glycemic control diminishes over the years, requiring the use of multiple therapies (66). Neither one of the tested treatments could halt the progressive deterioration of fasting glucose and HbA_{1c} values, as was originally hoped. However, these therapies did cause a 0.9-1.2% reduction in HbA_{1c} one year after treatment initiation that only reached levels of patients on conventional treatment after approximately nine years. Consequently, diabetes, although subject to a great deal of research, still causes considerable headaches to researchers and clinicians. Apparently, once the vicious circle of insulin resistance and overproduction has started, it is difficult to stop and very unlikely to revert.

Clinical research on Type 2 diabetes nonetheless continued to engage its enthusiasts and has resulted in the development of drugs with somewhat other modes of action than the long employed sulphonylureas and biguanides (73). New drug trials concentrate on counteracting the basic metabolic flaws in Type 2 diabetes: the relative insulin deficiency and insulin resistance. Deficiency is attacked with new insulin secretagogues (e.g., repaglinide) as well as rapid-acting insulins, preferably combined with sulphonylureas or a new group of insulin sensitizing drugs, the ‘glitazones.’ A new approach to enhanced insulin biosynthesis uses succinate ester derivatives, but postprandial secretion potentiators, such as glucagon-like peptide-1 and phosphodiesterase inhibitors, have also received the attention of investigators (73).

The motto of the American Diabetes Association includes not only improving the lives of those who have diabetes, but also curing the disease. Simultaneous kidney-pancreas transplants have proved successful in an increasing number of patients with Type 1 diabetes

and advanced diabetic nephropathy. A patient survival rate of 95%, with improved or normalized glycemic control, kidney function, and blood pressure, is no longer science fiction (74). However, because of the lifelong need for immunosuppression and surgical complications associated with transplantation, these therapies are not yet readily available for mass treatment.

Inhaled insulin preparations are another important area under investigation. Although not a cure for the disease, they bare the hope of many insulin-treated persons with diabetes. These preparations would require no needles and blood, just a discrete inhalation.

Educational Strategies for Coping with a Public Health Problem

The Diabetes Education Study Group was established in 1979. The primary goal of the study group was to promote and evaluate education as a means of improving diabetes care and outcomes. Although the group has organized a number meetings and workshops and published conference proceedings and recommendations regularly (63), consensus on how patient education programs should be designed and used within quality diabetes care is still lacking among professionals. In fact, the effectiveness of diabetes patient educational programs is controversial (75) and their evaluation differs despite presently existing guidelines (76). The major issues that have been subject to discourse in connection with diabetes patient education could be summarized under the following three categories:

1. Pedagogical principles applied;
2. Form of intervention; and
3. Professional category of educators.

In the following, I consider the issues listed within the categories Form of intervention and Professional category of educators, i.e. categories 2 and 3 above. Pedagogical principles applicable to diabetes educational programs are further discussed in Chapter 3.

Wagner and co-workers suggest that delegation of educational responsibilities to non-physician health care staff is “a hallmark of successful efforts to improve chronic illness outcomes” (4). Indeed, a metaanalysis of diabetes education programs revealed that effectiveness of interventions was independent of the professional category of educators (75).

A short review of the literature indicates that the most commonly employed diabetes educators are nurse-specialists and nutritionists (77-79). There are also examples of

pharmacists (80-82) and paramedical staff with limited education (83) as group leaders. Also rather common and proposed to be fruitful is the team approach, where, e.g., social workers and physical therapists contribute with their specific knowledge to that of the above mentioned professionals (84, 85). Physicians most often act as consultants to assess metabolic status or change treatment if metabolic control seems to get out of hand (83, 86), but can also be on the team actually taking part in the intervention (87).

The Study Circle Educational Program

PHARMACISTS SHOULD be generally invited to take a more active role in the care of persons with diabetes. I would like to propose three main reasons as to why this should be the case. I will then go on to describe the reason why *we* chose to employ pharmacists as diabetes educators and group leaders, aided by a diabetes nurse-specialist at the first two meetings.

There is evidence suggesting the effectiveness of pharmacist intervention to promote diabetes management. In a randomized controlled trial of a pharmacist-led diabetes management promoting program, participants in the intervention group were shown to decrease their HbA_{1c} values, which also differed significantly from those in the control group, at the end of the study period (88). Several other studies have demonstrated cost-effectiveness of pharmacist-intervention: reduced total health care costs accounted for by hospitalization and medication costs were described in one study (80), whereas total monthly health care costs as measured by claims were seen in another (89).

Pharmacists have the required knowledge and an attitude that seem to be unaffected by medical socialization processes. An extended education based on chemistry and molecular biology gives Pharmacists a stable basis to stand on when discussing food and drug metabolism in the human body. On the other hand, a pharmacist's education generally lacks the professional socialization of medical education that has been argued to keep up the paternalistic tradition and imbalance in power relations (13). In a Canadian study pharmacists' attitude scores were neutral toward the 'compliance,' 'NIDDM' (Type 2 diabetes), and 'difficult to treat' factors, items that would be considered to reveal 'disease or physician centered' attitudes in case of high scores. The study also indicated that pharmacists perceived themselves to have the necessary skills to become diabetes educators (90). Thus, pharmacists would have the attributes to take on the role of a group facilitator in a setting where equal power relations are both a goal and a means.

New professionalization efforts of pharmacists as a group of professionals have been indicated to increase interest in participating in not strictly pharmaceutical aspects of care, such as patient education. Because the traditional mystery of *ex tempore* drug manufacturing no longer exists, pharmacists are said to have lost their self-evident professional position in society (91). It is postulated that pharmacists engage in a new professionalization effort by utilizing their skills in non-traditional fields of pharmaceutical care, such as performing educational interventions (91). Thus, in the best case, pharmacist involvement in diabetes management would be an all-win situation.

THERE ARE TWO ADDITIONAL REASONS as to why pharmacists were chosen to become group leaders in the study circle program. The National Corporation of Swedish Pharmacies seemed to be a reliable partner for planning a national strategy to support the self-care of people with diabetes. This state-owned company is the employer of all pharmacists working at a pharmacy and is a political rather independent organization, more so than the local communities. The company also disposes over a well-spread national network of pharmacies which comprises an ideal distribution organ to an educational program aiming to reach thousands of people all over the country. Because pharmacists are available at all pharmacies, the manpower needed for an educational program seemed given. Moreover, the research group's leader already had an established relationship with the management of the corporation and a successful information campaign on diabetes had been conducted as a joint project in 1991 (92). Because the leaders of the corporation had been considering new strategies to improve their service for clients with chronic diseases, it seemed reasonable to continue the co-operation by testing an educational program for diabetes, a common chronic disease accounting for 10% of the corporation's yearly turnover.

THE STUDY CIRCLES are a tradition of adult group education in Sweden. These may concern a variety of subjects and are characterized by a democratic attitude and leadership based on the philosophy of equity and respect for knowledge (93). This background seemed ideal for creating a study circle for diabetes: a group of interested adults discussing not English grammar or politics, but Type 2 diabetes. "The aim of studies in a study circle is to gain knowledge, that does not only include learning facts about the subject, but also enables one to understand and change one's existence" (93).

Successful group educational programs for diabetes, in which the interventions resulted in decreased HbA_{1c} values, have been reported in Italy (79), Germany (83), Australia (84), and the USA (94). Indeed, group education addressing other diseases of the elderly, including macular degeneration, an eye disorder resulting in diminished visual acuity (95), and hypertension (96) have received positive evaluation by participants in the Nordic countries.

The international evidence on group education as a feasible form of teaching persons with diabetes to cope with their disease, together with the Swedish tradition of adult education in study circles, provided the theoretical background for the ‘diabetes circles’. The study circle material was based on previous research showing that understanding one’s bodily functioning in diabetes is pivotal to effective self-care. The processes of learning when and what action to take, and to “feel in the body” where blood glucose levels are, were described to take approximately one year (97, 98).

The goal of the 12-month long educational program was, therefore, to reinforce the participants’ experiences and use them as a basis for the acquisition of practical skills needed for self-management of diabetes (99). The educational program was also geared to provide the participants support for dealing with the emotional aspects of the disease. For help with the latter, a diabetes nurse-specialist participated on the first two days of the program.

During the intervention, the practical aspects of diabetes management, such as choice and preparation of food, performing self-monitoring tasks, and walks or jogs to decrease blood glucose levels, were emphasized. The groups met once a month and the self-monitoring diaries of participants comprised an important foundation for discussions. The guiding principle throughout the group sessions was that questions raised should be solved by the group and not answered by the pharmacist group leader. The group leader, in turn, received tutoring in the form of continuous access to his or her educator, Dr. Rosenqvist, and regular follow-up encounters twice a year.

2.2 RESULTS

Evaluation of Study Circles at the Pharmacy (I)

Data presented in this section are the result of an evaluation of the first study circles that had been going on since 1994. My task when I entered the project in 1996 was to try to determine the feasibility of using pharmacist-led study circles for educating adults with Type

2 diabetes. Three pharmacists had received special education and eight groups ($N=60$) had started to attend the course when evaluation began.

When conducting program evaluation, it is important to specify measures of outcome (43). The goal of the study circle educational program was twofold: First, to teach participants to steer their blood glucose towards near normal values through daily management of food intake, exercise, and medication dosage. Second, to provide participants with emotional support to deal with the experience of a chronic disease.

In program evaluation it is also desirable that the evaluator is confident with the contents of the program examined. Therefore, a session of observer participation (100) was included in the evaluation process. For the purposes of data gathering, a questionnaire was developed and sent to the participants who then had concluded the program ($N=21$). I also conducted six individual interviews with a purposeful sample (100) of group members that was selected to represent both sexes and three different age cohorts: 45-55, 56-65, and 66 and over.

It was hypothesized that a group education program using the experience of participants as the basis for discussions would result in improved glycemic control. Therefore, the main measure of outcome employed was HbA_{1c} values at baseline, after 6, and after 12 months of participation. However, in utilization-focused evaluation it does not suffice to determine the extent to which a program has attained its goals. Patton (43) illustrates this point nicely in the following passage.

“Program evaluation can and does involve examining (...) implementation, program processes, unanticipated consequences, and long-term impacts. Goal attainment, then, takes too narrow a focus to encompass the variety of ways program evaluation can be useful,” p. 23 (43).

To address the above issue, the six participants were encouraged to reflect on both positive and negative aspects of the program as a whole and as it affected their personal experience of living with diabetes. In response, three of the participants described that they had developed an understanding of their bodies and diabetes that had led to their gaining control of the disease: instead of being debilitated by restrictions, they could concentrate on actively affecting their blood glucose. The three other participants did not experience such a change (all of these persons were afflicted by diabetes for more than five years), but felt that the study circle was a pleasant social experience addressing important practicalities.

The participants also made some suggestions and these were later fed back to the current group leaders and used in the standardized three-day group leader course for pharmacists under development. Suggestions included, e.g., that exercising together should be an integral part of the program, the number of breaks should be increased, and that participants would not be obliged to hold “mini-lectures” on different subjects in front of the group. Participants further remarked on certain members’ talking too much in the group. Finally, two participants found it disturbing to look at pictures about diabetic leg ulcers.

FINDINGS FROM THE QUESTIONNAIRE ($N=21$) indicated that study circles held in pharmacies were a feasible way of educating persons with Type 2 diabetes. In general, participants had improved their perception of diabetes and subjective control over their disease. Almost all participants thought that they had been given a chance to discuss their feelings about diabetes and felt that it had been of support to do so. Nineteen participants felt that the study circle had helped them gain responsibility for their diabetes. Additionally, no one felt that it was unimportant to have near normal glucose values or that they had only little or nothing to contribute to their diabetes treatment. Participants received (and gave) emotional support in the groups, which were described as a stimulating environment for learning self-care. Comments to the open-ended questions included:

“I can now influence my disease in a positive way!”⁴

“I got emotional support from meeting others and realizing that I wasn’t alone...”

Many participants also acknowledged a desire to meet again with the group for a kind of “diabetes-specific socializing opportunity.” Newly diagnosed persons (diabetes for less than two years) were found to be significantly less anxious about their health after the intervention, and many members of the group – both newly diagnosed and experienced – had learnt new strategies for dealing with diabetes in everyday life.

HBA_{1c} MEASUREMENTS were analyzed to evaluate program effects on glycemic outcomes. At the time of the final analysis, all eight groups had concluded the group educational program. This gave us access to additional observations. Because of some dropouts ($N=12$) and missing data sets ($N=9$), we were left with $N=39$ complete data sets (of the original 60)

⁴ In the following this style will mark citations from the participants in our own studies.

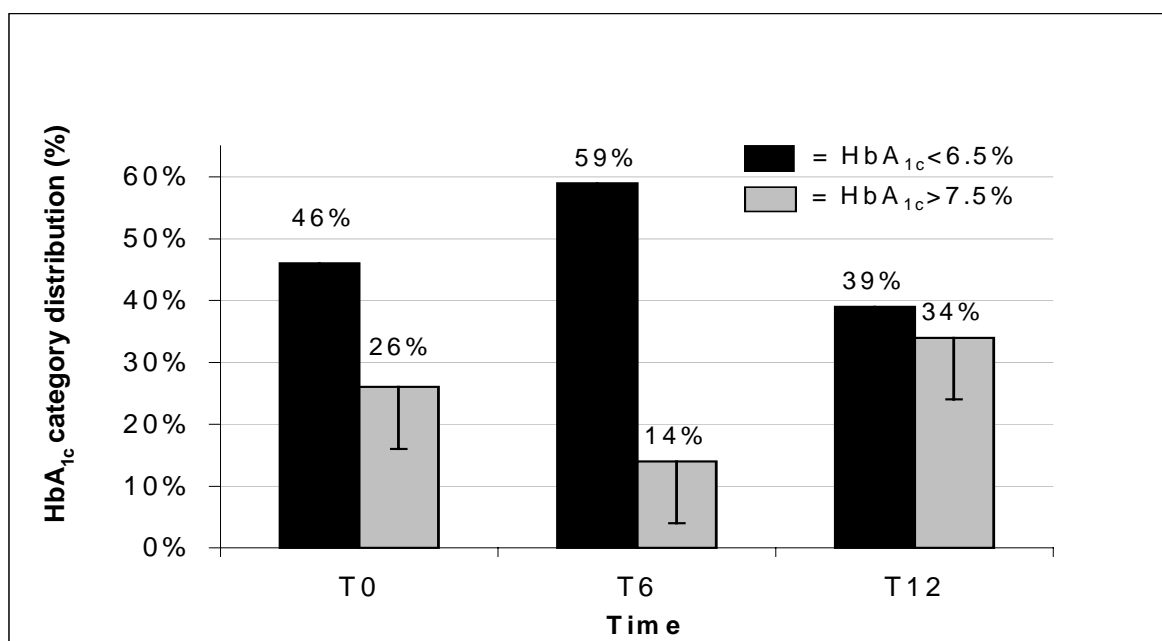
in the analysis of HbA_{1c}. HbA_{1c} values improved significantly after six months, but increased to baseline levels again at 12 months (Table I).

Table I. HbA_{1c} values at start, after six, and after 12 months N=36

TIME	HbA _{1c} % MEAN ± SD	PAIRED T-TESTS
t ₀	6.7 ± 1.36	-
t ₆	6.3 ± 1.35	p ₀₋₆ <0.05
t ₁₂	6.8 ± 1.54	p ₀₋₁₂ =0.37

There was also a redistribution of HbA_{1c} values during the one-year educational period. Figure 3. presents the distribution of HbA_{1c} values considered to reflect good metabolic control (≤6.5%) and too high levels (>7.5%) in relation to risk of long-term complications.

Figure 3. HbA_{1c} distribution over time in the study circle, divided into ‘good’ (HbA_{1c}≤6.5%) and ‘insufficient’ (HbA_{1c}>7.5%) glycemic control. N=39 (N=36 for t₆)



It is evident from Figure 3. that the same pattern of initial improvement and then returning to baseline characterizes the distribution of different degrees of metabolic control among participants.

By the end of the intervention, all participants owned their home-use glucometers; however, no difference in self-test use was seen (7.4±11 before versus 6.7±7 tests weekly

after 12 months in the program). It appeared that self-testing behaviors had become “rationalized.” The great variation in test use of 0-42 tests/week decreased to 1-25 tests/week and most participants had settled for one test/day, taking extra tests only when they were considered necessary. Twenty participants stated that test results were useful in making decisions on food intake.

2.3 METHODOLOGICAL CONSIDERATIONS

Using interviews in program evaluation

Either interviewing participants in groups or individually is effective in gaining information on positive and negative aspects of a program under development (95, 100): practical and emotional aspects can be highlighted.

“The naturalistic approach is especially appropriate for developing, innovating, or changing programs in which the focus is improving the program, facilitating more effective implementation, and exploring a variety of effects on participants,” p. 286 (43).

In such evaluations, however, there is always a risk that the participant’s desire to please program providers will bias his or her answers (101). Our program was also free of charge which could have led to the participants’ feeling obliged not only to attend the interview, but provide a positive evaluation.

To minimize these influences, I always started the interviews by explaining that I was a research student not actually involved in the study circles, but trying to find out how they were working for the participants. This, however, could have introduced a new bias, namely, the power relations of the researcher-patient encounter that is inherent in the interview situation. On the other hand, I was rather young when I conducted these interviews, which probably equated the power relations somewhat.

I did answer participants’ questions about myself and my role in the research project and confessed to those who asked that I was a beginner and really hoped that the tape-recorder would not play games on me. Nonetheless, it is increasingly recognized that the respondent’s perception of the interviewer influences the interview interactions and that perceived higher status seems to obscure personal characteristics of the interviewer (102). Therefore, the effects of power inequities on the material should be carefully considered when interpreting the findings.

CONCLUSIONS

- *Based on the experiences of participants, study circles for persons with Type 2 diabetes were found to be a feasible way of learning about self-care and gaining diabetes-specific social support.*
- *The pharmacist-led group educational program, which functions outside the official health care setting, contributed to fulfilling the goals of the Saint Vincent declaration (103) by “promote[ing] independence, equity, and self-sufficiency” of participants, as evidenced by their accounts in the questionnaire and the interviews.*
- *Allocation of tasks, such as practical skills-education and provision of long-term practical and emotional support for self-care, to non-physician health professionals is in accordance with experiences from randomized controlled trials on successful chronic disease management (4).*
- *Future research should explore the proportion of persons with diabetes that benefit from such an educational approach and the relation between qualitative measures of program success (positive emotional feedback and practical skills improvement) and long-term successful disease management.*

WHO SHOULD CONTROL DIABETES?

3.1 THEORETICAL PERSPECTIVES

Public Health as Social Control

As researchers with a medical background in the field of public health, we were certainly convinced that our approach to educate people how to deal with their bodies in relation to diabetes was a benevolent and democratic one. However, certain criticism concerning preventive educational efforts should be mentioned here.

According to Lupton, "health education is a form of pedagogy which (...) serves to legitimize ideologies and social practices by making statements about how individuals should conduct their bodies, including what type of food goes into bodies [and] the nature and frequency of physical activities engaged in bodies", p. 31 (11). She continues to assert that health education invokes "guilt and anxiety if the advocated behavior is not taken up" p. 31 (11). Kleinmann refers to this as the social control function of health care systems (14) and Lupton argues that public health exerts disciplinary power: because "health is deemed a universal right," measures taken to protect it "must be the concern and goal of each individual" p. 32 (11).

In present day Western society, so preoccupied with appealing physical signs of youth and health, a disease often associated with overweight, such as diabetes, is practically a "moral sin" (104). There seems to exist a "general moralization of health achievement," p. 43 (11) in society, resulting in the condemnation of others and self-blame when perceived cultural ideals are not fulfilled. Judgment of the sick person by health care workers and society is often influenced by type of illness, whether it is perceived "deserved" or not (11). This is what Kleinmann calls the "normative perspective of the socially constructed biomedical ideology," p. 58 (14), i.e. those who do not comply with the biomedical norms are termed deviant (14).

The diabetes study circle, a health educational program for tertiary prevention⁵, has been described earlier as an "educational strategy for coping with a public health problem"

and economic calculations established its usefulness as defined by utilitarian principles. Thus, when deciding about treatment and prevention of a “public health problem” from a health economy perspective, the goal to keep in mind is to “attain (or rather maintain) the highest possible quality of life during the longest possible time for each patient and, hence, all patients,” p. 145 (105). Health economists use certain factors, including time, discount rent, approximated age at disease debut, and the probability of getting sick when at risk versus prevention having an effect to see whether “society’s resources are best used by investing in prevention or by a ‘wait and see’ approach,” p. 145 (105). The costs and burden of diabetes (106) are such that to “wait and see” is neither morally defensible nor economically feasible and it is commonly accepted that measures need to be taken for secondary and tertiary prevention of the disease.

THE INDIVIDUAL’S PERSPECTIVE, however, might be different. Large studies have shown that tight glycaemic control (i.e. near-normal blood glucose values) decreases the risk for late complications (65, 107) and mortality (62). According to a prospective calculation, money invested in the study circle model of diabetes education is won back if it affects long-term glycaemic control by decreasing HbA_{1c} values (108).

However, the empowerment view requires that “the costs and benefits of diabetes self-care be viewed in the broader, personal, and social context of patients’ lives” (15). Pressing blood glucose towards near normal levels may have negative effects on the lives of persons with diabetes and their family despite a medically satisfying glycaemic result. A disturbing and potentially dangerous event is hypoglycemia. This occurs when blood glucose levels become exceedingly low and the person experiences sweating, intensive hunger, trembling, and, if sugar is not administered, fainting and coma. Spouses of patients with recent severe hypoglycemia showed significantly more fear of hypoglycemia, marital conflict about diabetes management, and sleep disturbances caused by hypoglycemia than spouses of patients without such a recent event (109). Overall, fear of hypoglycemia can have a negative impact on psychosocial functioning and quality of life (110).

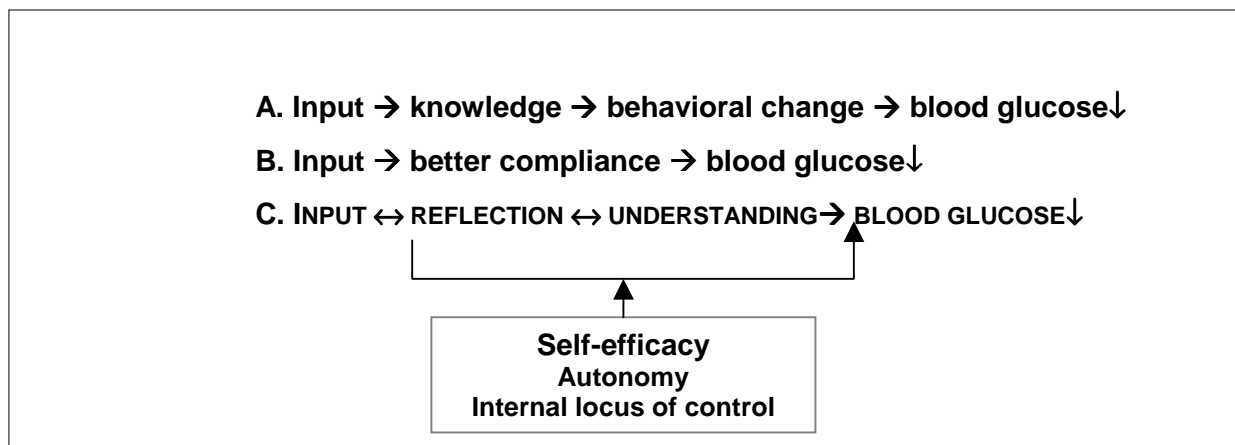
⁵ Secondary prevention: identifying diseases at an early stage (e.g., impaired fasting glycaemia in case of diabetes); Tertiary prevention: rehabilitation or treatment of diseases that have been identified after symptom presentation.

In a Type 1 diabetes sample, patients with good glycemic control were less sociable and lonelier than those less well-regulated (111). This finding coincides nicely with that for diet-treated participants in our study (II).

Pedagogical Principals and Metabolic Outcomes in Diabetes Patient Education

If I wanted to formulate what I believe to be the most basic, most crucial, and most controversial question in diabetes patient education it would read as follows: What is the linkage between educational input and metabolic outcomes? Some of the theories that have guided educational efforts are depicted in Figure 4. The traditional view (A.) has been that

Figure 4. Underlying theories of diabetes educational programs about factors affecting metabolic outcomes



increasing diabetes-specific *knowledge* of the staff would help the person with diabetes learn how to make behavioral changes and hence lead to better metabolic outcomes. Another traditional goal of diabetes education and treatment (B) has been to increase ‘*compliance*’ (15). However, greater compliance with self-care behaviors (85, 112, 113) and an increase of diabetes-specific know-ledge (78, 94) were not found to affect glycemic outcomes.

The last approach (C.) has its origin in hermeneutic theory development which could be (somewhat unduly) summarized as ‘no learning without understanding, reflection, and interpretation’ (114). According to this theory, the goal of modern diabetes education is to achieve an “integrated understanding” (63) based on personal experience and basic knowledge about diabetes. Ideally, such ‘deeper’ learning in the case of diabetes would mean a special skill to ‘read’ one’s body and react to its signals with adequate action (97, 98).

Reflection and *understanding* are concepts that underline the pivotal role that persons with diabetes have in achieving effective daily management of the disorder. In this perspective,

empowerment can be viewed as both the goal and the means of patient education in diabetes. Acknowledging the individual's competence to make decisions about everyday care yields a sense of *autonomy*, which is assumed to help individuals "take charge of their own diabetes" (15). This initiative, in turn, results in their acting as equal partners in the planning and delivery of diabetes care.

Supporting these assumptions is the evidence (depicted in the gray box of Figure 4.) that *internal locus of control* (94), reflecting the individual's sense of power to influence his or her situation, and health-care staff attitudes conducive to autonomy (17) have predicted a decrease of HbA_{1c} in diabetes educational programs. In a randomized controlled study of persons with arthritis, *self-efficacy* was distinguished as the mediating factor between educational intervention and improved disease outcomes along with decreased physician costs (16).

Whether this kind of 'taking charge' leads to metabolic control has not been fully elucidated. Implicit to 'taking charge' is the possibility that the person chooses not to control diabetes so tightly or at all: "Health is not the highest goal in life. Happiness is" (27). On the other hand, a sense of personal control could contribute to a state of well-being. Current evidence suggests that supporting the autonomy and empowerment of persons with diabetes produces beneficial outcomes (4, 25, 115).

Other factors known to influence success in educational programs are of a demographic nature. Younger persons and those more obese and more hyperglycemic were less likely to reach target levels of HbA_{1c} in the United Kingdom Prospective Diabetes Study (116). Overall, earlier studies have demonstrated an initial decrease in HbA_{1c} levels, but long-term glycemic control has been disappointing, as evidenced by a metaanalysis including 73 articles on patient education regarding diabetes (75). Therefore, it was our intention to identify demographic factors predicting long-term glycemic control on the individual and group level.

3.2 RESULTS

Predictors of Success in a Group Education Program for Type 2 Diabetes (II)

Following the successful pilot study, diabetes circles were started at several localities in Sweden. During the period between 1995 and 2000, 35 study circles with 248 participants had begun at 12 pharmacies throughout Sweden. However, at the time the present analysis

was conducted, only $N=105$ participants (including those of the pilot study) had concluded the educational program with complete data sets of 6- and 12-month values (HbA_{1c} t_6 and t_{12} , respectively). Investigating predictors of “glycemic success” required a definition of the latter. This proved to be a difficult task: in our efforts to acknowledge individual progress and at the same time consider clinical relevance. Thus, we ended up with a rather complicated, but applicable system that is presented in Table II.

Table II. “Glycemic success” was defined as A) decreasing HbA_{1c} on a progressive percentage scale for different initial values (column 2) where the higher the initial value, the more decrease required to qualify as successful; and B) achieving target values of $HbA_{1c} \leq 6.5\%$ at six months only or at both 6 and 12 months (columns 3 A & B). $N=105$

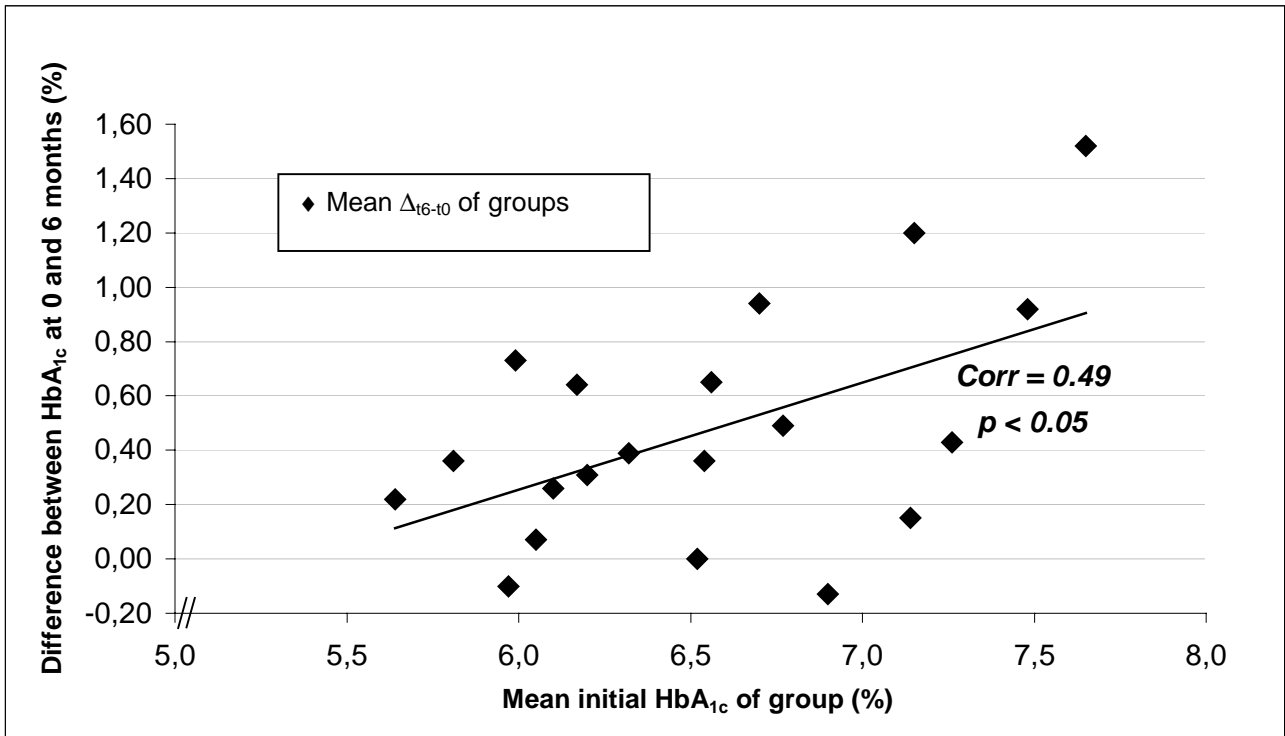
1. INITIAL HbA_{1c} VALUE	2. PROGRESSIVE PERCENTAGE SCALE	3. ACHIEVING TARGET VALUES OF $HbA_{1c} \leq 6.5\%$.	
		3.A Initial $HbA_{1c} > 6,5\%$	3.B Initial $HbA_{1c} > 5,3\%$
< 5.3% $N = 16$	-	-	-
5.3-6.5% $N = 38$	Any decrease $N = 17$	-	$\leq 6.5\%$ AT t_6^\dagger
6.6-7% $N = 19$	5% or more $N = 9$		AND
7.1-7.5% $N = 10$	10% or more $N = 4$	$\leq 6.5\%$ AT T_{12}^*	
7.6% < $N = 22$	15% or more $N = 8$		$\leq 6.5\%$ AT t_{12}
Sum $N = 105$	Sum $N = 38$ successful	Sum $N = 21$ successful	Sum $N = 45$ Successful

The mean age of the participants was 66.7 years (range 41-84 years). The participants mean Body Mass Index was 27.1 (range 18.8-44.8) and their diabetes duration averaged 6.7 years (range 0-20 years). Treatment was distributed as follows: 23% on diet only, 40% on oral hypoglycemic agents, and 37% on both oral agents and insulin.

THE MOST SIGNIFICANT PREDICTOR OF “GLYCEMIC SUCCESS” on both individual and group levels was found to be initial HbA_{1c} . It seemed as if higher initial HbA_{1c} values were easier to “press down” and hence predicted greater decrease in HbA_{1c} levels during the program (coefficient: -0.39 ; $p < 0.001$ on the individual and -0.49 ; $p < 0.05$ on the group level). To illustrate the above Figure 5. presents a correlation plot between the mean initial

HbA_{1c} value of $N=20$ groups and the difference between initial HbA_{1c} values and those measured at six months post-baseline, Δ_{t6-t0} . Although originally negative values, to increase comprehensiveness of the figure, differentials (Δ) are depicted as positive values when a decrease was observed and as negative when HbA_{1c} levels increased between the two points of measurement.

Figure 5. Correlation between initial HbA_{1c} and decrease of HbA_{1c} at six months. Mean Δ_{t6-t0} of groups plotted against mean initial HbA_{1c} of groups



Although a reduction in the mean HbA_{1c} by 0.14 % units at 12 months post-baseline was not statistically significant, the proportion of participants with HbA_{1c} \leq 6.5% had increased significantly from 51% at start to 63% after 12 months ($p < 0.05$).

High BMI, marking overweight, was another significant factor influencing outcomes: successful participants had a mean BMI=26.0, whereas non-successful participants had a mean BMI=28.7 ($p=0.01$). According to the Analysis of variance calculations (ANOVA), individuals with BMI \leq 27 tended to show a lesser initial decrease than persons with BMI \geq 30, who, in turn, experienced a “rebound effect“ at 12 months. Those with lower BMIs managed to retain metabolic control at the one-year follow-up ($p < 0.001$).

Other demographic variables that influence success were related more to what we could call the ‘status of the diabetes disease,’ i.e. where on the progressive curve of diabetes development the disease was situated. The typical positive relationship between duration

and HbA_{1c} t₀ (r=0.249; p<0.05), as well as that between HbA_{1c} t₀ and HbA_{1c} t_{6&t12}, (r=0.720; p<0.0001) and (r=0.668; p<0.0001), respectively, known from earlier research was found in our study as well. The above necessarily means that, in general, the more advanced the disease, the more difficult to achieve ‘good’ HbA_{1c} values of ≤6.5%. Hence, e.g., duration of diabetes was significant in those sets of t-tests, where the success-criteria comprised HbA_{1c}≤6.5%, whereas it had no effect in the ANOVA or regression analyses, where any decrease at all was sufficient to qualify as successful.

EFFECTS OF LONELINESS ON SUCCESS were complex and dependent on mode of treatment. It is also worth mentioning that those living alone reported a significantly higher degree of loneliness than those married or cohabiting, but 21% among the married or cohabiting also experienced loneliness. We conducted extensive analyses to understand the role of this variable, reflecting an important subjective aspect of “demographic status.”

Table III. The effects of loneliness (unadjusted for BMI, initial HbA_{1c}, and duration) on HbA_{1c} values at six and 12 months. Participants are dichotomized into groups above and under the 6.5% level

ALL VALUES AT BASELINE	t _{6&t12} ≤6.5	t _{6&t12} >6.5	Total	p-value
<i>Do you feel lonely?</i>	<i>N</i>	<i>N</i>	<i>N</i>	
Yes, sometimes	7	14	21	<i>χ²-test:</i> <i>0.006</i>
No	31	14	45	
Total	38	28	66	
VALUES >6.5% AT BASELINE				
Yes, sometimes	1	14	15	<i>Fisher's exact test:</i> <i>0.051</i>
No	8	13	21	
Total	9	27	36	

To begin with, no significant difference was found between persons exhibiting feelings of loneliness (N=35) and those not feeling alone (N=70) when HbA_{1c} at baseline was studied; nor was there a significant difference between metabolic outcomes based on reported loneliness: -0.2% decrease in HbA_{1c} for the non-lonely group and -0.05% for those experiencing loneliness. On the other hand, when participants were dichotomized into groups having values above and under the HbA_{1c}=6.5% level after 6 and 12 months, the loneliness factor became significant even when initial HbA_{1c} values were taken into

consideration. According to these comparisons, described in Table III, participants experiencing loneliness were less likely to attain and maintain HbA_{1c} values ≤6.5%.

Thus, it seemed that feeling lonely would negatively affect outcomes as measured by achieving HbA_{1c} values ≤6.5%, which is in accordance with what one might suppose. Yet, things were not that simple. An interaction between loneliness and treatment was persistently revealed in the regression analysis for the differential Δ_{t12-t0} ($p < 0.05$), but the factors comprising the interaction did not become significant on their own.

To investigate the interaction effect further, a separate regression model for each treatment category was tested. *Oral agent treatment* had a *positive effect* on individuals who *did not feel lonely* ($N=30$), resulting in a greater decrease of HbA_{1c} values than those who did feel lonely (CI [-0.38, -0.96], $p < 0.05$, $N=13$). However, adjusting this model for BMI, initial HbA_{1c}, and duration, loneliness no longer had a significant effect on the oral agent-treated group. For the *diet treatment* group, *greater decreases* were observed among those who *reported loneliness* ($N=8$) than among those who did not ($N=16$), even after adjustment as above ($\Delta_{t12-t0} = -0.5$, $p < 0.05$). Additionally, feelings of *loneliness* seemed to be associated with rather *tight glycemic control*: 80% of those who claimed feelings of loneliness had an initial HbA_{1c} ≤6.5%.

In summary, effects of loneliness were complex. From the above-mentioned evidence, it seems that persons on diet therapy who report loneliness have better metabolic results than the non-lonely in the same group, both as measured by HbA_{1c} values ≤6.5% and in the regression model for differentials. This does not apply, however, to persons on oral agents where an initial significance was diminished by adjustment for other demographic variables.

Implications

Would diet be more “suitable” for lonely persons? Being lonely might possibly mean secluded meals with the advantage of easier confinement to diet therapy. Conversely, to keep track of diabetes, individuals might avoid socializing around meals with resulting loneliness.

It is also possible that persons on diet therapy who are not lonely, but live in a setting with little diabetes-specific support, could benefit from adding oral agents to their regimens. Naturally, our sample size is far too small to draw such general conclusions, but the interaction of social life and treatment regimen should be given careful thought. Diet is a cornerstone of diabetes treatment, even when insulin or oral agents are added. Persons with

diabetes might need support to educate their spouses/partners regarding dietary needs and diabetes to satisfy both treatment and social requirements associated with meals, regarding the importance of food in daily living.

3.3 METHODOLOGICAL CONSIDERATIONS

Measuring HbA_{1c}

Validity

HbA_{1c} is a minor hemoglobin variant formed by non-covalent bonding of glucose to the N-terminals of α - and β chains (117) of hemoglobin in circulating red blood cells. Measurement of HbA_{1c} is now routinely used in clinical practice to follow up glycemic control as it reflects mean blood glucose levels of 24-100 days before blood sampling (67). There is a curvilinear relationship between glucose concentration in blood and HbA_{1c} values (117); the latter is a predictor of long-term disease outcome, whereby the lower the level, the lower the risk of complications (66) and mortality (62).

There is a biological variation of no clinical significance among hemoglobin subtypes, which may occasionally interfere with measuring HbA_{1c}. Of the approximately 250 samples the laboratory handled for us, only one displayed unusual hemoglobin that caused such problems. In these cases, special techniques are available to specify the variant for future analysis.

One of the Swedish reference laboratories for HbA_{1c} (Falun) analyzed all the samples reported in the studies of this thesis. Ion exchange chromatography was performed on a Mono S[®] for HbA_{1c} column (Pharmacia Biotechnology, Uppsala, Sweden) using valley-to-valley integration (118). The intra-assay coefficient of variation (CV) for the Falun laboratory was < 1% (118). The normal range of HbA_{1c} in the laboratory was 3.5-5.3%, yielding values of about one percentage unit lower than for the Bio-Rex[®] method used during the Diabetes Control and Complications Trial (65).

The fact that different methods and assays are employed for HbA_{1c} analysis (119) is a rather common problem in comparing results from different studies. Owing to their use of different assay methods, the target level for HbA_{1c} in the UKPDS was, e.g., higher (7%) than the 6.5% recommended by the IDF (68). It is, however, not the exact target value, but the blood glucose level it corresponds to that is of importance. This is because near-normal

levels are the aim of all diabetes treatment and educational programs. We believe that an effective way of comparing studies would be to look at proportions of HbA_{1c} at a target level within the population.

Participant Collaboration

Advancements in clinical chemistry have made it possible for users to take capillary samples for HbA_{1c} analysis at home and send it via mail to the laboratory (118). Individuals take capillary blood as they would for a simple blood glucose measurement, apply it onto a strip of Chroma filter paper, and insert it into a polypropene tube containing phosphate-buffered sodium chloride with EDTA. This tube is then put into a capsule tube and mailed to the laboratory in a special envelope for biological material.

Overall, participants seemed to understand the written instructions for capillary sampling as it was intended and surprisingly few missing data were accounted for by user mistakes. On approximately 10 occasions, the laboratory was unable to perform the analyses because of too little blood on the filter paper. On two occasions, the blood samples were sent to our institute instead of the laboratory by mistake.

Statistical Design and Analysis

To control for variability among subjects we chose the repeated-measures design for evaluating study circle effects on glycemic control. Blood samples were analyzed for HbA_{1c} on three occasions, with the participants serving as their own controls. The repeated-measures design is especially convenient and useful when responses to a certain treatment over time are concerned (120).

A disadvantage of the method is the *position effect* (120), i.e. the subject's response to a treatment may be different depending on its position in a sequence of interventions. This effect is typically explained by the participant's initial enthusiasm, which is then followed by disinterest or disappointment. The position effect is not a statistical, but a methodological flaw that could not be avoided in this case because it was not possible to randomize participants to different stages of the educational program. The study circle rather represented a process that the group went through together, and it is most likely that program effects did diminish over time, as indicated by the position effect.

The adequate statistical analyses in repeated-measures design are paired comparison tests. Using the same subjects for comparison eliminates problems with matching and differences in variance. The variable of the simple random sample undergoing analysis is the difference, in our case, between two HbA_{1c} levels. A disadvantage of using differentials is the loss of degrees of freedom: $2n - 2$ had we not used paired comparisons, but $n - 1$ for the simple random sample of differentials (120). On the other hand, we calculated three differences, which made more elaborate analyses possible: delta between 6 months and start (Δ_{t6-t0}); delta between 12 months and start (Δ_{t12-t0}); and delta between the 12-month and 6-month value (Δ_{t12-t6}). These differences were analyzed using multiple regression models with the demographic data serving as explanatory variables.

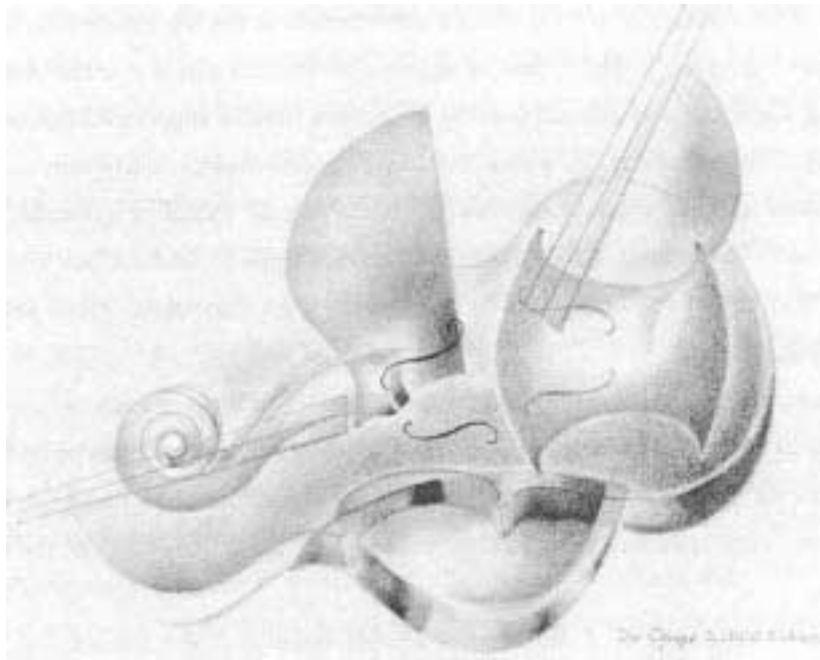
There is some debate in the literature about levels of analysis when studying effects of interventions. It is reasoned that when interventions target health professionals or groups, statistical analysis should be performed on the cluster level (121). In our studies, an initial intervention targeted pharmacists, but the main intervention of interest targeted the persons with diabetes themselves and therefore we considered analysis on the individual level appropriate.

CONCLUSIONS

- ***The social control aspect of health education must be born in mind to seek avoid its oppressive features.***
- ***Success in the diabetes educational program was influenced by initial HbA_{1c}, BMI, and loneliness in interaction with treatment. High initial HbA_{1c} was correlated to greater decrease in values, whereas high BMI, marking overweight, interfered with long-term control, but not initial success during the intervention.***
- ***Diet treatment alone seemed to benefit individuals who experience loneliness more than those who do not feel alone, as measured by glycemic outcomes. It is possible that persons on diet therapy who do not feel lonely, but live in a setting with little diabetes-specific support, could benefit from adding oral agents to their regimens. Although our sample size is too small to draw such general conclusions, the interaction between social life, especially its meal-related aspects, and treatment regimen should be given careful thought.***

PART TWO

DIABETES, WOMANHOOD, AND INTIMACY



Chapter 4

"Women's and men's health cannot be viewed isolated from family structure, (...) from social and cultural surroundings, gender-ideologies or a culture-based understanding of disease," p. 12 (122)

WOMEN, DIABETES, AND WHO ELSE?

4.1 THEORETICAL PERSPECTIVES

Implications of Network Theory

Social Support and Social Network – Clarifying (or obfuscating?) the Terms

Before analyzing the implications of network theory on diabetes self-care, certain terms need to be clarified in that there is considerable variation in the literature concerning what these terms represent. The definition of *social network* we chose to use in this study is the following: the social and cultural context the person lives in and carries out his or her activities. The network actors within the social context may be individuals, groups, or organizations and the relations between the actors can be formal or informal. Cultural context, on the other hand, is the meshwork of politics, language, tradition and more or less explicit ideologies and behavioral expectations that characterize the individual's surrounding.

Social networks have a *structure* and *function*. Most authors divide the *structure* component of the social network into formal and informal relations and some authors term the latter social network and use social relations instead of social network as an overriding category (123). Some authors exclude formal (124) or non-lasting (125) relations from the network definition.

Further categorization of the network *structure* consists of the number and type of relations, frequency and duration of contacts, diversity, density, and reciprocity in social relations. All these terms, as well as the categories of function that are described later, are subject to widely different definitions and how researchers operationally define these terms, resulting in difficulties to compare and summarize study results (126).

Although the dyadic of formal and informal relations is inherent to the presented model as well, it is not explicitly stated because it is the role of different network actors in women's chronic disease that was interesting, not the influence of their formal or informal natures. Moreover, we found it problematic to categorize the *social environment* because it has

both formal and informal components. According to Pirie, a mediation process between social and personal values takes place, involving “daily conversations where the social world becomes ‘our world,’ duly translated and personalized to the extent that we no longer recognize a clear-cut distinction between the public and private spheres of meaning” (127). Thus, media, political decisions, fashion industry, our neighbor’s comments, and the teacher’s speech at the parent meeting all mediate both the social values and personal preferences of the actors.

The *function* of the social network includes social (emotional, instrumental, and informational) support, relational strain, and social anchorage/integration. Relational strain consists of conflicts or excessive demands.

In accordance with the above, *social support* is interpreted as “the actual psychosocial and tangible aid provided by the social network” (128), a support function obviously not always available. Therefore, we avoided the interchange of the terms *social support* and *social network*. The social network is a very capable source of positive feedback, social support, and self-esteem (129). On the other hand, social demands - which the individual may or may not be able to fulfil - are an inevitable part of such a social system. A social demand can be “important in shaping a person’s thoughts, feelings, and actions while not necessarily being a source of stress. The critical factors in creating stress are *conflict*, *ambiguity*, and *overload*,” p. 238 (129).

There is ample literature on the health-promoting effect of social support, whereas only a paucity of studies has highlighted the impact of conflicting demands and role overload that might cause psychological stress:

“Psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being,” p. 19 (129).

The aim of our study was, therefore, to elucidate role conflict or excessive social demands that might lead to psychological stress in the daily management of diabetes. As mentioned in Chapter 1, two main reasons led us to focus on *women* with diabetes: the apparent scarcity of specific literature on women’s chronic diseases and women’s spontaneous comments on ‘role conflicts’ that they had experienced in our early interviews.

USING NETWORK THEORY TO EXAMINE COPING AND OUTCOMES in chronic disease has proven feasible in several studies. Although we do not know the exact mechanisms involved, there appears to be a general assumption that the social network of the individual is of importance in chronic disease management, leading to policy statements both within science and welfare policies.

“The sociology of illness must consider people’s everyday lives (...), it must examine the relationship with family members, friends, and work associates” (5).

“The health care system should introduce a general policy making it explicit that efforts to improve the patient’s social situation could be as important as other therapy alternatives. (...) Disregarding these kinds of efforts strongly contradict basic professional and ethical norms,” p. 207 (130).

There is some collaboration in the literature for the theory that support from the social network is of greater importance for the (health-promoting or maintaining) self-care of men (131), exemplified by the evidence that men living in family situations smoke less and exert more health-preventive behaviors than men living alone (132). Thus, men would receive more (practical) support to take care of their health. The question is how this support affects illness-responses in diabetes, i.e. what kind of behavior does the social network of men and women reinforce? Kaplan and Hartwell suggest that “men have a more causal disposition toward their illness [Type 2 diabetes] and that they receive support for this posture,” whereas “networks found satisfactory to women may support behaviors that lead to good control” (133). With this conclusion we are back to the statement in the motto: “Women’s and men’s health cannot be viewed isolated from family structure (...) [and] gender-ideologies,” p. 12 (122).

Several studies have examined the role of social network in Type 2 diabetes. Women and men are typically compared for network size, social support, and satisfaction with the latter and these are used as explanatory variables for self-care behaviors or metabolic outcomes. The results are contradictory in many ways and a simple conclusion is not easily drawn.

In a Swedish investigation, males reporting high emotional, informative, or practical support had better fasting blood glucose levels than highly supported women one year after diagnosis (134). This finding is probably due to men receiving ample practical support, such as prepared meals and company to health care visits. All men in a Mexican sample of

diabetic persons had their food specially prepared for them by a (female) family member, whereas only 13% of females received such support from their family members, resulting in significantly better disease control among the men (135). In a study examining self-management in diabetes, being young and female was associated with higher levels of social-environmental barriers related to diabetes self-care, especially the diet item (136). In another study, greater network size predicted less conscientious adherence to a remedial program in women but had no effect on men. On the other hand, high satisfaction with the social support system resulted in lesser worry, but worse metabolic control for men (133).

As outlined above, network theory has been found to be a feasible framework to examine individuals' health-related behaviors in general as well as in diabetes in particular. In accordance with a recent policy statement from the National Public Health Committee in Sweden (130), we applied network theory as a basis for systematic analysis of our own and others' findings in examining the "disease-related personal network conditions" of women with diabetes.

4.2 RESULTS

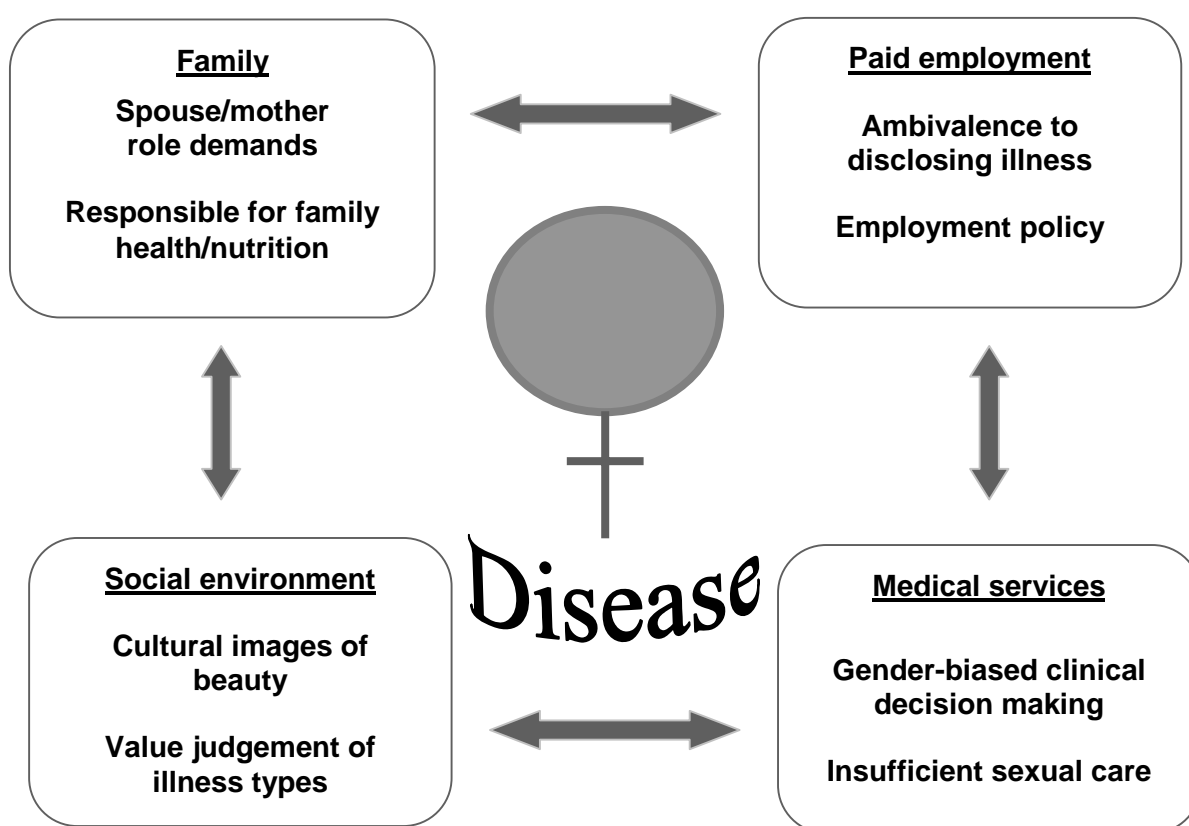
Social Network and Role Demands in Women's Type 2 Diabetes (III)

THE MATERIAL USED FOR THIS PAPER consisted of three components:

1. Women's descriptions summarized under the category "*Role Conflict in Diabetes*" in the qualitative analysis of our first interviews for evaluation of the study circles.
2. Women's descriptions summarized under the categories "*Hinders for Everyday Diabetes Management*" and "*Blood sugar controls – a routine or a drag?*" in the qualitative analysis of interviews conducted for understanding differences between those that managed well and those that did not.
3. Results from a literature study summarized under the headings listed below:
 - Mothering role and chronic disease;
 - Women's social bodies and chronic illness;
 - Chronic disease and womanhood;
 - Multiple roles of women;
 - Women and the family's health;
 - Role conflicts experienced by women;
 - Gender-bias in Western health care;
 - Gender differences in coping with disease;
 - Women's health and illness in the 19th and 20th centuries;
 - Women's health and their social networks.

A MODEL ON THE SOCIAL NETWORK OF WOMEN WITH CHRONIC DISEASES, based on the works of the Norwegian social anthropologist, Barnes (137) and the Swedish Genell-Andrén (138), has been constructed. We adapted the general network model by highlighting formal and informal network aspects – such as family, paid employment, social environment, and medical services – that were judged relevant to the social network of women with chronic diseases. Figure 6. is a schematic presentation of these network components and the interactions between them.

Figure 6. The “Disease Manager” Woman and her Social Network



Network Component 1 - Family

Again, “women’s (...) health cannot be viewed isolated from family structure,” p. 12 (122). However, this is not a one-way effect: family structure and the role of family as a network component cannot be viewed without considering women’s traditional roles as responsible for family health (31) and nutrition (139).

Authors in the Netherlands have shown that a part of women’s higher rates of health care utilization seen in national statistics, previously interpreted as reliably indicating greater morbidity in women, was accounted for by their consulting physicians for preventive health

care measures for their families (140). Furthermore, family dietary needs (husbands' high blood pressure) and preferences (teenagers would not eat salad) as well as price all played a greater role than aspects of personal nutritional care in the grocery shopping patterns of women with Type 2 diabetes (141).

It would seem that women consider their health as significantly depending upon the well-being and satisfactory functioning of the family. Consequently, the "overall health outcome" for the family becomes prioritized when women make decisions about their own health-related behaviors (142). By the same token, women were shown to be non-compliant with any treatment that did not fit their daily schedules they had before receiving the diagnosis of a chronic disease, such as routines of employment and caring for a sick husband (143). Considering the above, it should not be surprising that the number one cause of anxiety among 500 women was "vicarious stress" (144), i.e. stress originating from the lives of loved ones in the family (divorce, disease, etc.).

If we accept the assumption that women's traditional role as *caregivers* still influences the family structure and behavioral pattern in Western societies, the implications of such a role should be considered in women's chronic diseases. In our interviews, women with Type 2 diabetes described role demands that interfered with their self-care regimens:

"I work for eight hours, with a long journey home. Then I shop, make the meal. By the time I'm ready it's eight o'clock. I don't have time to take a walk...when am I supposed to take care of the home?" Woman 50, with diabetes, married, working, 1 son.

"I have no time to myself. My husband has dementia; I can never leave him alone and go and take a walk!" Woman 76, with diabetes, married, retired.

It seems reasonable to assume that chronic diseases, with a need for extensive self-care (appropriate diet, exercise, rest, medical visits), could put women into a conflict situation where they have to choose between performing self-care, occasionally on the account of care provided to the family, or abandoning self-care with the consequences hereof.

Based on the above, it would seem that traditional gender role expectations in families and the fact that diabetes is not always perceived as a "real" illness to be socially responded to, may limit women's ability to cope with the "Disease Manager Role" (Figure 6.).

Network Component 2 - Paid Employment

Although not always exclusively satisfactory, the workplace provides a forum for engaging in social relations. To lose this network and financial security through unemployment poses a constant threat to many workers of today, especially those with a chronic illness. A woman's willingness to disclose her illness to the employer "is plausibly due to her position in the labour force and sense of job security." (145):

"I would not tell anybody. If I say that I have diabetes, they would not hire me, they would fire me. (...) When an employer hires somebody to work, they do not want to hire somebody with illness, especially chronic illness" – Cantonese woman, 39 years old, Type 1 diabetes, blue-collar worker in the Canadian study of Andersson et al. (145).

In Sweden, there is strong legal support for employment security and an insurance system that provides support to those suffering from debilitating illness. Therefore, women residing in Sweden probably do not fear losing their jobs because of they have a chronic disease. On the other hand, illness demands may come into conflict with the work schedule and expectations at the workplace. Measuring blood glucose at work e.g. was experienced by several women as troublesome and a sign of disease that they did not wish to share with their co-workers as indicated in our interview protocols and those reported in other studies (146).

"I always sneak out to check my blood sugars. I got hold of a key to some kind of a resting room and do my blood tests there so no one sees." Woman with diabetes, full-time employee at an electrical factory.

"When we're out having lunch at work, I don't sit there and take blood sugar tests...you don't do that...I don't do it. And then it gets out of hand..." Woman with diabetes, full-time employee at an office.

In discussing why women, more often than men, try to conceal their diabetes, William-Olsson postulates that "the disease provokes women's autonomy in a different way than men's," p. 84 (1). She argues that having diabetes and disclosing this fact could be too threatening for the ideal of a 'real' or 'successful' woman. Having a 'sticky,' 'disgusting' disease, where manipulating blood and urine are part of everyday life would contradict the 'cleanliness' of a 'real' woman (1).

It seems that women with other diseases may also feel a need of concealing their disease:

“I can’t be sick at work, I can’t be sick at home. I go into the closet and take a nitro[lycerine tablet against angina pectoris].” Woman with diabetes and heart disease, married, employed, cited in the Canadian report of Clarke (32).

Ambivalence about disclosing illness and factual or alleged negative employment policies in the case of chronic disease may thus represent a conflict situation for women in a paid employment setting. This in turn may lead to difficulties dealing with both employment and disease demands, forcing some women to leave (or not take) employment or compromise effective disease management.

Network Component 3 - Social Environment

As mentioned above, the social context we live in is translated and personalized to become a part of ourselves (127). “Our standards of physical attractiveness are based on youth and vitality,” p. 75 (147) and it is therefore important to consider the effect of these social expectations of women’s body image in chronic disease:

“I did not feel clean and fresh at all {after the diagnosis}...” Woman with diabetes, living alone.

The ideal physical appearance of a woman, as painted by the fashion industry and mass media, becomes printed in girls’ and women’s minds “to the extent that [they] no longer recognize a clear-cut distinction between the public and private spheres of meaning” (127).

Allan, examining women’s self-care activities in relation to their weight, concluded that the “cultural pressure on women to be thin” led to negative self-image for 40% of study participants” (148). It is argued that “food and weight have become such a major sociocultural preoccupation for girls and women that it is almost impossible to grow up female today without ever feeling fat, worrying about weight, and developing ambivalent feelings towards food” (149). Adolescent girls in a Norwegian study started smoking earlier than boys, a phenomenon that was explained by their concerns of gaining excess weight (150). In a Swedish survey, the only participants (including cancer patients) having worse mental-health profiles than severely obese women were those who suffered from unresponsive chronic pain (151). Eating disorders accounted for the fact that teenage girls

had higher rates of hospitalization than their male peers for diabetic ketoacidosis: young girls abandoned insulin injections out of concern for becoming fat (152).

When these strong cultural expectations are confronted with the realities of chronic disease, self-image may be disrupted:

“I’m a damaged product in the marriage market.” Woman with diabetes,
cited in Packard et al. (153).

Having a chronic disease is a very physical experience: it may cause women to feel ‘sticky,’ ‘unclean,’ and overtly unattractive. These possible negative effects of chronic illness on body image may be amplified by unrealistic cultural ideals of female physical beauty which may therefore interfere with successful coping.

Network Component 4 - Medical Services

Historical prejudices about “weak” and “irrational” women (154) in traditional Western medicine still influence health care provisions for women. It would seem that the “link between women and ‘nerves’ has remained peculiarly strong” despite advances in modern medicine (45).

Several studies from Britain, Australia, and the USA have shown that physicians more easily attribute women’s complaints to psychological problems than actual somatic ones (154-156). It has been postulated that “the sex of the patient biases the GP into reaching a psychological diagnosis due to a preconceived belief about the likelihood of such a diagnosis in females” (155). Women physicians are not devoid of gender-bias in their attitudes either. This biased orientation is due to the structure and content of medical education (13), producing “expert[s] in a power-position, with masculine sex-stereotypic overtones” (12), susceptible to “prejudices and other evaluations based on gender roles” in clinical decision-making (157). Consecutive studies reported startling examples of sexual and racial discrimination in the care of coronary heart disease (158-161) and kidney failure (162).

Such prejudice naturally affects contact with the health-care system for women who live with a chronic disease. Women seem to be aware of the risk that their symptoms could be judged as a ‘psychological’ problem:

“I think he [the physician] knew we had difficulties at home, but I didn’t mention that. You don’t want it to be taken for something psychological.” Woman with chronic back pain (12).

In a Swedish survey, women were found to be less satisfied with diabetes care than men when it came to the support they received for coping with the emotional aspects of diabetes (163). A woman in our interviews described her feeling of helplessness in a health care setting:

"I realised that if you are a man they tell you about the possibility of aids and everything you might need - a woman doesn't merit anything..." Woman with diabetes, living alone.

A possible explanation for this is that provided by William-Olsson, who herself has diabetes. According to her, there is a gender-role game taking place between the diabetes nurse specialist, a 'successful career-woman,' and the 'sick and unsuccessful diabetic' (1). For women, this encounter could provoke a need to assert themselves as the women they are (and want to be), whereas men would try to impress the female behind the nurse-role by being a 'good patient.'

There is sufficient evidence to assert that clinical decision-making is often influenced by gender-specific preconceptions. Because managing a chronic disease involves regular contact with the health care system these aspects should be considered when discussing network-specific aspects of women's chronic disease.

4.3 METHODOLOGICAL CONSIDERATIONS

Implications of Role Theory

According to Gordon, role may be conceptualized as a normative or a behavioral entity, depending on the orientation of the social scientist dealing with it (164). In that the distinguishing quality of the above presented model is interdisciplinary, the following assumptions about role were accepted without fully following either one of the social, psychological, or anthropological paradigms, but employing them in an interdisciplinary fashion.

- Role is a *social and cultural construct* and, as such, has normative implications;
- Role is a mediating factor between the expectations of the social system and the individual's behavior that requires the *interaction between self and role*;
- Roles are defined, *redefined, and modified through the interaction* with others occupying complementary roles (165); and

→ One individual may occupy *several parallel roles* and individuals may *behave differently in the same roles*.

The “Disease Manager Role”

Parsons was the first to conceptualize the *sick role* as a social construct (29). Although his theory has been criticized, Parsons has made an important contribution in realizing that when an individual becomes sick, the medical diagnosis per se is insufficient for describing this event and its consequences.

It is important for a sick person to legitimize the illness-state by both professionals and significant others because this “official status” influences the coping strategies considered relevant for the individual. Those who deny their illness or, on the contrary, continue to seek new diagnosis, and thus retain illness behavior (166), have a greater risk to meet conflicting demands in that their statuses are not defined (167). A typical example of this is chronic illness in which initial uncertainty of diagnosis and, later, fluctuating functional capacity yields undefined illness status for long periods. Therefore, it has been suggested that Parsons’ sick role concept lacks relevance for chronic illness (168).

Based on empirical research, Gordon introduced the concept of the *impaired role* (164). He concluded that “the role pressures relevant to the impaired role serve to aid and maintain normal activities” as opposed to the sick role in which the aim is to “insulate and protect the ill person,” p. 99 (164). Although the “impaired role” concept is certainly more suitable for chronic diseases than the classic “sick role,” it still implies strong dependency on the health care system in defining how the person with the chronic illness should be defined.

“In addition to prescribing medical treatment, the physician should prescribe the social response to the ill person. However, it is not enough for the doctor to prescribe a social response; (...) he must determine, by judicious probing, if his social prescriptions are being followed,” p. 100 (164).

Gordon also argues that “the use of prognosis as the key to determining the social response to an illness condition seems eminently reasonable,” p. 100 (164). However, diabetes is not a readily visible condition (and not all choose to disclose it, as we have seen), nor is the prognosis readily assessable.

Therefore, we believe it is a combination of the ideology of self-care and certain characteristics of the impaired role that are of value when discussing diabetes. We have attempted to summarize these aspects in the “*Disease Manager Role*.” Thus, self-care is an unavoidable disease demand in diabetes to prevent acute and chronic complications and restrictions caused by the disease must be accepted by both the individual and his or her significant others.

The term “*Disease Manager Role*” implies an active role on the part of the individual in coping with diabetes and underlines the time and energy demanding character of practicing self-care. If and what winnings are associated with having diabetes is a question of disease severity, cultural context, personality, autonomy, and gender of the affected person. Because the concept of “*Disease Manager Role*” summarizes the most important aspects of self-management in diabetes acknowledged in this thesis, I will make use of this term in my description of diabetes care in Borderland in Chapter 7.

CONCLUSIONS

- ***The individual's social network is a source of social support as well as social demands.***
- ***Because of traditional gender roles, obligation profiles associated with meals, cultural expectations on women's physical appearance, and prejudice about the psychological etiology of women's symptoms, the family, paid employment, the social environment, and medical services all represent possible sources of conflict with women's successful diabetes management.***
- ***The social network model could be used in clinical diabetes practice to help women and their caregivers plan appropriate interventions and set up treatment schedules that acknowledge barriers to self-care and comply with women's daily role obligations.***
- ***The newly coined term “Disease Manager Role” implies an active role of the individual in coping with diabetes and underlines the time and energy demanding character of practicing self-care.***

Chapter 5

FEMALE SEXUAL DYSFUNCTION IN TYPE 2 DIABETES – A PERSONAL MATTER?

5.1 THEORETICAL PERSPECTIVES

Feminist Views on Sexuality and Medicine

It is often contended that the medical profession has power and social authority to form norms of sexuality. “Sexology is viewed as an ideology, a combination of discourses legitimized under the rubric of science which seek to control and confine certain forms of sexual expression,” p. 27 (11). Sexual behaviors that are classified as non-traditional are argued to become medicalized and marginalized (38).

Shervin claims that, given the close relationship between sexuality and power in our culture, it is ethically unacceptable for health care personnel to give sexual advice without considering the social, political, and juridical aspects of sexuality (38). Otherwise, they risk advocating social norms of acceptable and “normal” sexual behavior, which is considered misuse of their power position (38). AIDS is often cited as a current example for active intervention in people’s sex lives and most intimate decisions by the medical profession and public health authorities (11, 38).

Women’s sexuality has traditionally been viewed as “especially threatening to the moral order and social stability of society,” p.132 (11). From the 19th century until the early feminist movements of the 1930s, female sexuality, other than for the purposes of reproduction, was a taboo subject. Sexual desire was to be mastered and over-active female sexuality was defined as mental or moral illness (45). Female masturbation was considered especially dangerous and to cause a variety of illnesses. Clitoridectomi (removing the whole or part of the clitoris) was therefore performed by physicians in the nineteenth century to prevent girls from “becoming nymphomaniacs and homosexual” as well as to preclude suffering from fatigue, epilepsy, visual damage, and insanity (169).

WHETHER MEDICALIZATION of “common events in women’s lives,” p.189 (38) should be considered as oppression or salvage is an important discourse in feminist literature. There are many pages written on medicalization and hence impossible to give a full review here. Essentially, what feminists criticized was that meanings associated with “female hormonal

‘states’ on which to pin evidence of female inferiority,” p. 155 (170) and “the decision to view (...) menstruation, pregnancy, menopause, body size, and female behavior as diseases” comprised and resulted in “the general oppression of women,” p. 189 (38).

“The seemingly abstract code of medical science in fact tells a very concrete story [on the social order], rooted in our particular form of social hierarchy and control,” p. 197 (171).

Historically, menstruation served as a reason to exclude women from many professions and important positions in society. The emotional and physiological changes associated with women’s menstrual cycles were reasons enough to confine women to their homes (45). Feminists give much of the blame to the medical profession for having provided “evidence” that “sexual activity and reproduction are more fundamental to women’s than men’s nature and that therefore women are better suited to the domestic sphere,” p. 133 (11).

Although much has changed in the power relations between men and women in Western societies, it is still asserted that “menstrual rules and taboos serve to mark out the woman as Other, as different,” p. 141 (11). Lupton describes the ads in which tampons and menstrual pads provide their wearers *cleanliness*, as representative of “the socio-cultural anxieties around the possible contaminating nature of menstruation,” p. 141 (11). Medical textbooks also include negative terms in their descriptions of menstruation and “unacknowledged cultural attitudes can sip into scientific writing through evaluative words,” such as ‘ceasing,’ ‘losing,’ ‘expelling,’ and ‘denuding,’ p. 48 (171).

Pre-menstrual syndrome (PMS), an array of unpleasant symptoms experienced by some women before their menstruation, has attracted considerable attention. It is now listed as a psychiatric entity and has been used by the defense as an alleviating circumstance in two murder cases in Britain. Pre-menstrual syndrome has also been described as a culture-bound syndrome, which would serve to answer the role conflict of women in today’s Western societies where women are expected to be “both productive and reproductive: to have both careers and families” (172).

On the other end of the scale are the truly troublesome or even dangerous aspects of women’s reproductive functioning. It has been contended that although biomedicine had contributed to oppressing women, it also acted to liberate them by offering women control over their fertility, pain management for dysmenorrhea (painful menstruation) and at delivery, and relieve of hot flushes and other menopausal symptoms by hormone replacement therapy (HRT).

Most feminists will agree that “moral criticism of (...) medicalizing women’s existence,” p. 190 (38) does not imply that all experiences of menstruation, pregnancy, and menopause are risk- and pain-free, and it is often medical expertise that is needed to alleviate symptoms and prevent complications. However, feminist theory maintained its criticism that the “seemingly abstract code of medical science,” p. 197 (171) helps to convey oppression of women based on their physical functioning.

Female Sexual Dysfunction

Until the 1970s, there were only two expressions in use to characterize sexual dysfunction: impotency for males and frigidity for females. The latter term has been accused of “not only lacking precision and information, but being disrespectful and pejorative” against women and women’s sexuality (173). The phrase ‘impotency and frigidity’ reflects the “misconception that men always wanted, but sometimes could not, whereas women always could, but sometimes did not want to,” p. 233 (174).

A new classification system has recently been developed by the first *International Consensus Development Conference on Female Sexual Dysfunction* (175). The new system follows the general structure of the foregoing systems, but now definitions include the adjectives ‘persistent and recurrent’ and ‘personal distress’ is added as a diagnostic criterion to almost all categories. Furthermore, the new category of noncoital sexual pain has been appended. Each diagnosis is given a subtype: (i.) acquired versus lifelong, (ii.) generalized versus situational, and (iii.) organic versus psychogenic. The 1999 Consensus Classification System includes:

1. *Sexual desire disorders:*
 - Hypoactive sexual desire disorder (Lack of fantasies/thoughts or desire)
 - Sexual aversion disorder (Phobic aversion to/ avoidance of sexual contact)
2. *Sexual arousal disorder*
(Insufficient subjective, genital, or somatic response)
3. *Orgasmic disorder* (Absence of orgasm after sufficient sexual stimulation)
4. *Sexual pain disorders:*
 - Dyspareunia (Genital pain associated with sexual intercourse)
 - Vaginismus (Involuntary spasm interfering with vaginal penetration)
 - Other sexual pain disorders (Noncoital pain induced by nongenital stimuli)

How common are these disorders in a general population? I present results of some studies that have attempted to measure and describe the prevalence of female sexual dysfunctions

in Table IV., according to earlier diagnostic criteria. The picture emerging from these findings is that female sexual dysfunction is common in the general population, with approximately 20% reporting disturbances of interest/desire, 15% experiencing decreased arousal/lubrication, and 20% impaired orgasm; dyspareunia is present in less than 10%.

Table IV. The prevalence of sexual dysfunction in women in general female populations. Sexual dysfunction is divided into disturbance of the three phases of the sexual response cycle: interest/desire (1), arousal/lubrication (2), and orgasm (3). Dyspareunia makes up a separate category.

Author	WOMEN STUDIED	PHASE 1	PHASE 2	PHASE 3	Dyspareunia
Laumann (176)	National Health and Social Life Survey 1992 (18-59 years)*	22%	14% <i>(27% of women 50-59 years)</i>	≈25%	7% <i>(21% women 18-29 years)</i>
Lewin (177)	Swedish general population sample	Interest 32% Desire 15%	12%	22%	10%‡
Osborn (178)	From community (35-59 years)	17%	17%	16%	8%
Rosen (179)	Healthy gynecology outpatients (18-73 years)	(38.1%†)	13.6%	15.4%	11.3%
Spector (180)	23 studies reviewed, data from community samples are cited here	10-36%	11-48%	5-10%	8-23%

* 43% of women and 31% of men experienced sexual dysfunction

† Anxiety or inhibition during sexual activity

‡ Among women over 50 years of age

Unfortunately, studies differ in their classification criteria, how data were collected, and the age and social characteristics of the populations examined. Other problems are that women often experience disturbances of more than one phase of the sexual response cycle, that there exists a significant co-morbidity with other disorders, and that diagnostic criteria lack reliability and validity (173).

In a large American survey, different demographic factors were shown to be associated with self-reported sexual dysfunction (176). Young women and older men (50-59 years) had greatest risk of experiencing sexual dysfunction. Low physical, emotional, and general health satisfaction was related to a higher risk of experiencing sexual dysfunction for both women and men. In a comparable Swedish survey, subjective health status was inversely related to

sexual satisfaction: those who assessed their health as moderately or non-satisfactory were also significantly less satisfied with their sex lives (177).

Diabetes and Female Sexual Functioning

The connection between male impotence and diabetes has long been known. Research over the past few years has shown that diabetes is associated with sexual dysfunction in females as well (181). Although empirical results vary, evidence suggests that women with Type 2 diabetes have double the risk for disturbed lubrication compared with their age-matched, non-diabetic peers (181). Pain during intercourse – dyspareunia – and decreased sexual desire occur with greater frequency in women with diabetes, presented in Table V., in comparison with the general population. Orgasmic dysfunction, found in an early study (182), has not been shown to be associated with diabetes in later research.

Table V. The prevalence of sexual dysfunction in women with diabetes (the same classification as in Table IV).

Author	Women studied	PHASE 1	PHASE 2	PHASE 3	Dyspareunia
<i>Summary of Table IV.</i>	<i>General population</i>	<i>≈20%</i>	<i>≈15%</i>	<i>≈20%</i>	<i><10%</i>
Campbell (183)	”Diabetic”	23%	29%	23%	16%
Hulter (184)	IDDM	25%	20%	10%	-
Jensen (185)	IDDM (26-45 years)	20%	24%	11%	10%
Jensen (186)	IDDM (32-51 years)	24%	18%	19%	10%
Kolodny (182)	IDDM	NO	14%	35.2 %	3%
Newman (187)	”Insulin-treated”	21%	32%	15%	21%
Schreiner-Engel (188)	IDDM and NIDDM	YES	YES	YES	NO
				32%	
Tyrer (189)	IDDM (18-45 years)	45%	10%	17%	12%

Explanations for female sexual dysfunction entail the newly designated “vaginal engorgement” and “clitoral erectile” insufficiency syndromes (190). Decreased pelvic vascular flow is proposed to be responsible for these disorders. A discrepancy between available and required blood perfusion to the pelvic organs would thus cause late or diminished lubrication and decreased clitoral stiffening and sensitivity on sexual stimulation.

Diabetic neuropathy is known to be associated with sexual dysfunction (impotence) in males, but there is no sufficient evidence to support this claim in women (181).

On the other hand, depression and sexual dysfunction were found to be significantly correlated in women with diabetes neuropathy (191). In addition to the physical effects of the disease, women with diabetes were also found to experience significantly more concern than non-diabetic women regarding the frequency of sexual repulsion and performance anxiety and the impact of these feelings on sexual behavior (192).

5.2 RESULTS

THE MATERIAL PRESENTED BELOW is the complete analysis of the focus group interviews, the 20-item questionnaire and observational data we have collected for the purposes of exploring the relation between diabetes and intimacy, as experienced by a purposeful sample of middle-aged and older women ($N=33$). Research questions examined comprised whether these women perceive diabetes to affect their intimacy, if they relate eventual sexual problems to their diabetes and perceive this as problematic, and finally, if they wish to receive professional attention for their sexual disturbances, when present.

The complete analysis of the questionnaire and interviews is judged to be too heavy for publication as a single piece which is why papers focusing on single resulting categories have been produced. One highlights the aspects of guilt and shame experienced by the women in our interviews, both in connection with their diabetes and their sexuality (IV). The other article, presented in Chapter 6, is a deepened reexamination of the qualitative analysis category “Sex issues in physician contacts” (V). However, I would like to present the compressed version of the analysis below to provide a ground for judging both the process of analysis and the papers based on it.

QUALITATIVE ANALYSIS OF THE MATERIAL followed the pathway recommended by Malterud, “a pragmatically mixed procedure,” p. 90 (51) based on different qualitative analysis methods. I found her pragmatic, detailed, and instructive descriptions, similar to those in Patton’s *Content Analysis* (100), very useful during the practical work.

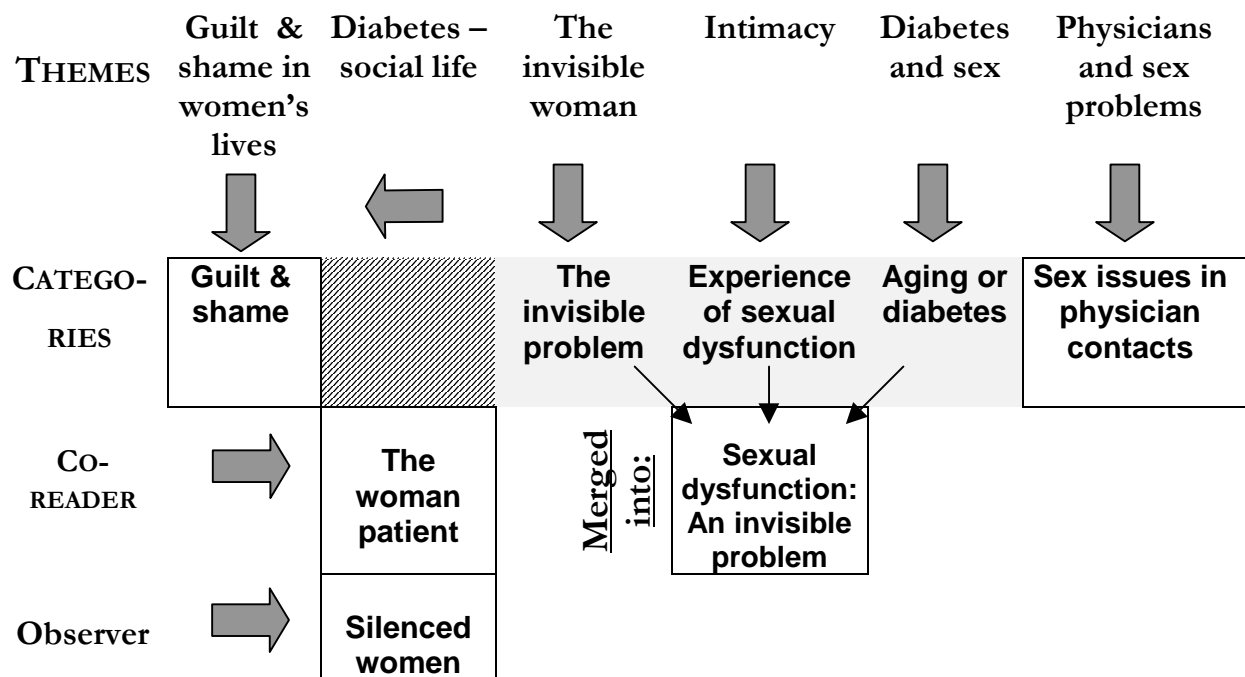
The four basic steps recommended by Malterud are:

1. Acquire an overview – Themes;
2. Find meaningful units and put them into categories – coding;

3. Describe the contents of each decontextualized category – Abstract, edit and condense; and
4. Recontextualize – validate and choose representative citations for each resulting category.

I am supportive of the notion that all researchers should aim to “leave(...) a clear decision trail” so that “any reader or another researcher can follow the progression of events in the study and understand their logic” (48). The computer software NUD*IST was easily applicable for the analysis steps presented above and resulted in an extensive documentation of my ‘decision trail,’ which has been one of my goals since it is thought to enhance the quality of the analysis performed.

Figure 7. Presentation of steps involved in the qualitative analysis. Initially, themes were identified from the original text. Categories later emerged from these themes. Certain categories were merged with each other to increase clarity, which are represented in the text by direct quotes from women’s voices. The observer contributed with the category of “Silenced women” and the co-reader with “The Woman Patient.” Resulting categories are framed



In Figure 7. above the ‘decision trail’ of identifying themes and later categories is presented graphically. Additional strategies to improve the quality of analysis were to use a co-reader and an observer who also contributed to designating resulting categories.

INTERVIEW PARTICIPANTS HAD a mean age of 65 years (44-80; SD=8.7) and they had had diabetes for a mean of 6.3 years (1-20; SD=5.2). Approximately two-thirds of participants were married or partnered. Almost all were postmenopausal, two-thirds (N=19) received estrogen substitution, and one third (N=10) considered themselves “currently sexually active.” Leading reasons given for not being sexually active (N=22) were that it was a matter of choice (N=5) or was due to lack of a partner (N=8). Partner’s illness (N=3) or sexual dysfunction (N=3) were also mentioned by the women. Sexual dysfunction was reported by 14 women, most commonly decreased interest (N=6), desire (N=8), and lubrication (N=8). The majority of those who answered the question (N=23) were satisfied with their sex-lives (N=15).

Resulting Categories of the Qualitative Analysis

Guilt and Shame

Guilt and shame seemed to be a recurring theme both when women talked about diabetes and when they discussed sexuality. Much of this guilt was perceived to be a result of their upbringing. According to these values, diabetes was the disease of unhealthy habits, overeating of fatty foods, and no exercise. Thus, there were undertones of self-blame and resentment among the women as they talked about their diabetes.

“I knew I had diabetes on my father’s side and still I had allowed myself to swell up so ...I only had myself to blame”

“A lot of those who get it in adult life (...) have actually EATEN their way into it by...well a disease of faulty living, some would call it exuberant...”

Others stated that there was absolutely nothing to be ashamed of when it came to having diabetes. One important aspect in generating self-blame seemed to be whether or not the women’s lifestyles could account for their developing diabetes. The perceived societal attitudes, “*every magazine I open seems to highlight diabetes as the disease of a faulty- or exuberant lifestyle*”, and preconceptions about diabetes some of them had grown up with, made it difficult for women to accept and cope with diabetes.

Most women seemed to agree that whether or not one could/should/dare discuss matters of intimacy with others was a generational issue. The women’s attitudes towards their own sexuality were influenced by the way sexual issues were (not) dealt with in their

childhood. Bodily signs of womanhood, such as menstruation and sexual desire, had been deemed shameful and to be disguised, according to women's childhood memories.

"I didn't know what a period was when I had my first one at age 11 and there is a lot of things like that you're ashamed of (...), so I find it real hard to talk about stuff like that".

The mother-daughter relationship was discussed in several groups apropos the above. Two different patterns emerged among women whose mothers did not discuss the physical realities of sexuality with them. Those who adopted opposite behaviors with their own children and those who remained unable to discuss intimate matters, but seemed resentful of this. Feelings of guilt and shame naturally limited women's choices and opportunities to talk about their sexual problems. Not all of them could discuss such matters with their partners and female friends were most often mentioned as plausible confidants, if at all.

Women's Experiences of Sexual Dysfunction - an Invisible Problem

A common speculation among the women who experienced vaginal dryness was whether this dryness was caused by diabetes or by menopause. Because physicians normally did not ask about, or mention vaginal dryness as a possible symptom/complication of diabetes, the women were left to find their own explanations for the cause of their problems.

"Sometimes I wonder if it has to do with the diabetes or if it's just my age or what the hell it is..., my temperament, or is he the wrong man (...) or do I feel lousy because I don't have a job or WHAT?"

Most women attributed their problems to "natural ageing". Some women, however, did associate the emergence of sexual problems with the onset of their diabetes. Several women mentioned decreased desire as a rather uncomfortable symptom. It seemed important to these women that the symptoms they experienced had, or could have, a medical explanation.

"It would be nice to think it could actually be a medical phenomenon, that it's not my situation".

Whereas male impotence in diabetes and other chronic diseases was a well-defined problem that most women had heard about, female sexual problems, such as vaginal dryness, or lack of desire were felt to be "invisible". The explanation for this, according to the women, was that whereas men seemed incapacitated, "good for nothing" when experiencing sexual dysfunction, women could usually function "whatever the case".

"Women of our age, who live alone, won't - are of no real interest, in a way..."

"Women - oh, they're not important (...) if you've no desire yourself, that's brushed under the carpet..."

The women sought more research and information on and more specific treatment for female sexual dysfunction. Viagra for women, high quality lubricants, and "soft" pornography on late television shows were suggested as the means to a better sex-life. Women, notably, used words such as "dare to" and "brave" when describing their efforts to deal with the "invisible" sexual dysfunction several of them lived with.

Some non-partnered women in this study said that sex was not an important issue for them, although there were women who expressed hope to meet someone they could like "in all ways". Hugs, intimate talks, and cuddling were more important than sex for some of the older women in the group, whereas others used the term "intimacy" in a broader, more "social" way: one woman stated that love for her grandchildren somehow took up the space her dead husband had left behind.

The Woman Patient

Living alone as middle-aged or older women in today's society was perceived to have implications on women's roles as patients. A woman described finding it difficult to present her needs when faced with a health-care system where she was constantly meeting different doctors and did not know what to expect of them. The group decided that "placing demands" on health professionals created greater difficulties for the older women, who also felt that societal and health care attitudes expressed towards them changed the older they became.

***"There's a distinct difference when you turn 65/...
...Yes, a lot of things change - You're not worth as much"***

When the groups discussed attitudes towards sexuality, they were asked if they would consider turning to a health care professional if they experienced sexual problems. The predominant answer was that they would not turn to their GPs (more extensively elaborated in the analysis category "Sex issues in physician contacts" presented in Chapter 6), but perhaps to a gynecologist. The diabetes nurse was mentioned by one participant, but no other health professionals were proposed. One woman described her confidant relationship with her (female) GP, allowing e.g. pelvic examination.

“Silenced” Women

The observer called the interviewer’s attention to the way issues raised by some of the participants appeared to be rejected by the group. It was not a question of simple disagreement, but an effort of the group or its powerful members to exclude other women from the actual discussion. The above observation pinpointed the phenomenon of “silenced women.” Interviews were therefore read through once again, specifically concentrating on this aspect: were there further examples of “silencing” and were there common denominators between rejected subjects?

In this section, I will present some examples and give the reader a chance to experience the conversational nature of the focus group technique. Women cited will be marked by W1, W2, etc, the same number marking different women in the quotes.

Example 1. – “threatening” views:

“W1: I wouldn’t say that to absolutely anyone [referring to diabetes]

W2: Neither did I [initially] because I did not feel the least bit clean and presentable

W3: But I never felt that way!

W4: That’s interesting what you’re saying – makes one wonder where you got that perception from

W2: I guess it’s something from my childhood, that...

W3: Isn’t it just some deep prejudice!”

In another group, based in a small town, a woman was quickly “silenced” when she told the others how she felt her gynaecologist had neglected her problems.

Example 2 – “degrading” views of a highly regarded person:

“W1: I tried to bring it up [vaginal dryness] with the gynaecologist and he just wasn’t interested

W2: I can’t understand that, because I have the same doctor and I really do not perceive him as you do

W1: I know, I also think it’s strange because I feel he is attentive

W3: Yes, he gives us time

W1: But not in this case, you see

W4: He does give time

W3: He’s a great doctor!”

Example 3 – disagreeing with a powerful group member. One of the women stated that she had an excellent GP she could confide in and who was capable of “both things:” attending to her diabetes and giving her a pelvic examination. A group member who was on

insulin and was considered something of an expert by the other members that were “only” on oral agents responded with great emphasis:

”I could never even contemplate that...such intimate matters with my GP!”

I feel that considering this potentially negative aspect of conducting focus groups is of both ethical and methodological importance, as will be discussed below.

5.3 METHODOLOGICAL CONSIDERATIONS

Using the Focus Group Method

I became interested in the focus group technique when I first read about it in Patton’s *Qualitative Evaluation and Research Methods* (100). I started reading methodological textbooks and became fascinated by the information generative power of groups that was described in these books. In addition, I had conducted interviews with the study circle leaders who witnessed the ease participants had in talking about everything, including difficult, emotionally charged issues. On the other hand, I felt concerned about setting up groups with people who did not know each other.

Later, when I decided to examine the relation of diabetes and intimacy in women’s Type 2 diabetes, I saw an opportunity to test the method. Interviewing women in already existing study circles would solve my concern about participants’ not knowing each other. I planned to time the interviews in conjunction with the final group meeting without the group leader or male group members present. Location was given and participants already had a scheduled activity for that day, so the compliance problems experienced in focus groups used for industrial purposes would not be a worry (193).

I had directed a theatre play and participated in a special course, designed as a one-week boarding school, for studying group dynamics⁶. It was the above and a number of individual interviews I had with me when I set out to interview five groups of women in four Swedish towns. There were between six and eight women, who knew one another, in the groups: interviews lasted one hour each. Two interviews were conducted during lunch hours the women were invited for a ‘submarine’ sandwich and some fruits on these occasions. On the other three occasions, it was the women who invited me to drink coffee with the group after the interview.

I was received very positively by the women and was surprised by the openness with which they shared their views and experiences with the group and myself. I made it clear in the beginning of the interview that everything said was confidential and I believe that this contributed to the women's feeling at ease to talk. Also, as the women pointed out, they considered the interview a rare and welcome opportunity to discuss intimacy with other women in similar situations.

The test interview, though, was a disappointment. I was not clear enough on what I wanted information about and it took the group almost the whole session to start talking about something else than food, weight, and future prospects of curing diabetes. By the time the "real" discussion started, time was out. Therefore, to the contrary of what had been set earlier, I decided to send all future participants a letter where I would explicitly state the subject of the interview: "Diabetes, womanhood, and intimacy". The effect was convincing. My first question became "*What did you first think of when you read the contents of this interview 'Diabetes, womanhood, and intimacy' in the letter you received?*", and we were 'on track' right away.

INDIVIDUAL OR GROUP INTERVIEW. Because I did not conduct individual interviews on the same subject, I cannot judge the superiority of either the focus group or the individual interview method. Instead, I can only communicate the perceived advantages of the focus group method.

A clear advantage was that data could be gathered from several women at the same time (33 women on only five occasions). This contributed significantly to the comprehensiveness of the material. It was a stimulating experience to listen to these women discuss eagerly, but still respected others' need for space. As time went on, I needed to say less and less; women learned to pose questions to each other, follow-up unfinished sentences and 'buffer' emotional exclamations. On the other hand, the fact that the women came from the same town and knew each other – which I was convinced would be positive – could have affected the scope and depth of the discussion because of the prospect that participants would likely meet outside the group.

GROUP DYNAMICS is an important aspect of the focus group technique since it could serve to fuel discussions and add a dimension to the discussions that would not be possible in a simple researcher-participant session (193). Positive or negative, the fact remains that power relations within the group, which had met for one year before the interview, probably influenced the discussions.

To appreciate these circumstances, an observer was present during one group discussion. Andrea Wahlberg was a student at our department and wanted to learn about the focus group method. The observation episode seemed at first as only of interest for Andrea to learn about conducting focus groups. However, when I went back to the original material one year after the interviews and the primary analysis, I found notes from our conversation which helped me recognize a new category, the one I called “*Silenced women*”.

Matters, subject to “silencing”, were either emotionally charged (cancer, self-disgust) or expressed by or against the “wrong” member of the group. We know that cohesive groups permit greater expression of hostility and conflict (194). If we consider “silencing” an act of aggression, it could be due to the group’s sense of tension, plausibly caused by the interview situation, and/or to the strict social positioning of group members (195). Thus, the groups might have expected this kind of behavior from their highly cohesive members (194) in a new setting where the formal group leader was not present.

Ethical Considerations

When I planned for the focus group interviews some research colleagues wondered whether such delicate matters could be discussed in a group setting. I was to find out, I said, and tried to trace authors who have used the technique for researching sensitive topics. Morgan e.g. conducted a study on the first year of widowhood (196) and Wight on working class boys’ thoughts and talk about sex (197) using focus groups. In a Canadian study, women over 60 were interviewed in focus groups to “investigate [their] attitudes toward sexuality and intimacy” and how these issues were addressed by the medical profession (35). In addition, a Norwegian study successively employed the technique with participants whose mean age was 80 years (95).

Group dynamics, a working tool for generating discussions in a focus group setting (198), may have disadvantages. Certain participants might not feel comfortable verbalizing their feelings in a group setting, whereas others might offer personal information they later regret. These aspects triggered an ethical discussion in our research group in which my

standpoint had been that participants were grown-up persons who gave informed consent to the interview and it was their responsibility what they decided to share with the group. However, I saw it as my task to secure that no one became hurt or suppressed during the interview sessions.

THE RESEARCH ETHICS COMMITTEE

at Uppsala University granted permission for conducting the study. Some minor changes were required in the information letter to participants, such as writing ‘asking’ instead of ‘inviting’ subjects to participate and we were advised to include the alternative answer ‘I don’t know’ in the questionnaire and to use ‘we’ instead of ‘I’ in the directions.

A change obviously appreciated by participants was the Committee’s

recommendation to add an alternative answer to a questionnaire item, addressing the reasons for not being sexually active, stated in Figure 8. On the test occasion women seemed reluctant to answer this question. After having added the extra alternative, “By choice,” the answering-rate improved substantially. I realized that assuming it could be a matter of choice not to be sexually active was enough for most women to be able to answer such a delicate question honestly and fully.

Scientific Criteria for Qualitative Research

Currently, there are four criteria in use to enhance and judge the quality of qualitative research. *Credibility* for truth value of the study, *transferability* for applicability of its results, *dependability* for control of its circumstances (both researcher and subject), and *confirmability* of its data (42). Several synonyms and expanded concepts are in use, such as *fittingness* in stead of *transferability* and *auditability* in stead of *confirmability* (48).

Credibility is enhanced by triangulation of data collecting procedures, negative case analysis, checking results with participants from whom the data had been collected, and data analysis by another researcher (42). We used the latter technique when a co-reader (Dr.

Figure 8. Extra response alternative as recommended by the Uppsala Research Ethics Committee, marked here with capital letters

Are you sexually active?
 Yes
 No

If not, why?

BY CHOICE (MY OWN OR BOTH PARTNERS)

No partner
 Partner’s illness
 Partner’s sexual dysfunction
 Own illness
 Own sexual dysfunction

Rosenqvist) read through the original, unmarked text to make sure that no themes were systematically excluded in the primary coding process.

Describing both typical and atypical elements of the study as well as establishing what the subjects in fact represent enhances transferability. Atypical views were mentioned in each section even if these occasionally had been expressed by a single participant. As to representativeness of the sample in terms of sexual functioning, it is worth noting that sexual activity (31%) and satisfaction (65%) reported by the women in this study compared well with figures established in a U.S. sample of 1,216 elderly people (199).

A threat to fittingness, the “elite bias” of subject selection (48), was present here. The women were participants of a self-referred diabetes education program, obviously attracting interested and self-efficient persons. The findings are nonetheless interesting because if these well-informed women, capable of advocating their needs otherwise, felt guilt and shame for their diabetes and sexuality, how might other women with fewer social, informational, and economic resources feel? Future research should aim to explore if our findings are relevant for women with different cultural and educational backgrounds.

Confirmability is achieved when a detailed audit trail is followed, using “residues stemming from the inquiry”, p. 319 (42), including raw data, field notes, work hypotheses, process notes, data reconstruction, instrument development, and preconceptions. The ‘decision trail’ involved in the qualitative analysis is demonstrated in Figure 5.1.

CONCLUSIONS

- ***The focus group method had the advantage of gathering many opinions during few sessions and the participants stimulated each other to discuss areas of importance for them. A disadvantage might have been that the women were part of a group before the interview with established power relations that could have affected what was said and by whom.***
- ***Sexual dysfunction is common among both menopausal women and those with diabetes and was experienced by nearly half of the women in the study.***
- ***Guilt and shame were recurrent themes, both concerning women’s diabetes and sexual functioning. This guilt and shame, along with social taboo, perceived negative societal attitudes, and women’s own conceptions that their sexual disturbances were caused by “natural aging” powerfully added up to render their sexual dysfunction “invisible.”***

Chapter 6

CONTRADICTIONS OF THE MEDICAL ENCOUNTER

6.1 THEORETICAL PERSPECTIVES

Women's Provider Preferences for Sexual Care

Females, more so than males, tend to prefer a physician of the same sex (200, 201). Accordingly, women select a female general practitioner to not only a greater extent than men do, but also more probably than men choose male physicians (202). Female general practitioners, in turn, have more female attendees (200) and take care of more female-specific and psychosocial health problems than their male colleagues (203).

Women's preference of a same-sex physician is especially apparent when the consultation is to treat sexual dysfunction (204) or deal with health issues linked to women (201). People are also more likely to disclose personal matters when there is a same-sex match-up between them and their physician (205). This, on the doctor's side, corresponds to less comfort and perceived lower levels of skill when performing sex-related examinations or obtaining sexual histories from persons of the opposite sex (206). In line with the above, female physicians report more comfort performing breast examination, obtaining Papanicolau (cervix) smears, and talking about sex with women (206).

WOMEN MORE OFTEN CHOOSE A GYNECOLOGIST over their GPs for communication about sexual problems (204) or when pelvic examination is to be performed, especially when the primary care physician is a male (207). Overall, women prefer gynecologists for basic gynecology care (207) and half of the women in addition prefer female providers for gynecologic consultation (207, 208). Most people do not want their GPs to receive a report on their genitourinary consultations (208) and approximately half want their GPs to know about their sexual problems, but rather refer than him/herself treat these (209).

On the other hand, a personal invitation from the GP resulted in higher attendance for cervical cancer screening with smears, especially for women with greater risk because of sexual behavior or smoking (210). In addition, GPs are an important resource in identifying sexual dysfunction in the population: physicians who routinely conducted a sexual history reported a greater proportion of their patients experiencing sexual problems (33 versus 9.5%) than those who did not (211).

The Contradiction

There is some evidence to suggest that there is a gap between hypothetical evidence, i.e. when healthy persons are asked about their attitudes (36, 37), and data from patient charts and self-reports on consultations. Only a small percentage of those experiencing sexual disturbances actually seek their GP's help for this problem (212, 213), as also evidenced by this study. Additionally, there seems to be a discrepancy between patients' perceptions of their GPs capability to treat sexual dysfunction (213) and their own ability to report such dysfunction to them. Another disparity is between physicians' perceptions of people's capability to receive and answer direct questions (214) on sexual functioning and attendees' expectations of their GPs to raise the issue (35, 36).

The apparent contradiction between findings in the focus group interviews and those in the literature prompted this final field of investigation. Women did not feel comfortable discussing issues of sexuality with their GPs, although they saw them regularly for their diabetes. I realized that I in fact could have biased the women into discussing the physician's role in coping with sexual problems by probing for this issue in the focus group interviews.

6.2 RESULTS

Contradictions in the Medical Encounter: Female Sexual Dysfunction (V)

THE MATERIAL PRESENTED IN THIS SECTION is a result of a deeper reexamination of the qualitative analysis category "Sex issues in physician contacts" describe in Chapter 5. The analysis of this subcategory was carried out in a similar way to that in the initial process (described in Chapter 5), but this time with a specific issue to explore: What influenced women in their decisions to discuss or omit the subject of sexuality with their GPs.

Circumstances in the Health Care Setting

Time constraints were perceived to hamper women from bringing up sensitive, intimacy-related issues:

"They {the physicians} are too stressed, too rushed, so they listen and hear what you have to say, but what you've said at one point, they'll have forgotten at the other..."

Lack of privacy at primary health centers constituted another obstacle. Thus, women felt that besides their own shame hindering them from freely discussing the sensitive topic of sexual functioning, circumstances in the primary care setting were far from ideal for this purpose.

Generalist versus Specialist

Most women agreed that sexual function and dysfunction were the domains of the gynecologist:

"Diabetes is diabetes, it's medicine and this is more, well yes, gynecologists' {ground}."

"Bringing that up - matters below the waist - that's what's so difficult when you're older."

Two women who had female GPs felt that they could both discuss sexual problems with and receive a pelvic examination from their family physicians. Although most participants agreed that gynecologists were the adequate health professionals to assist them with sexual problems, few of them had actually consulted a gynecologist for their disturbances.

Personal Characteristics of the Physician

The GP's personal features seemed to have the greatest influence on whether or not sexual matters were discussed. When women explained why it was not possible to discuss sexual problems with their GPs, one description was, *"he's so shy"* and another, *"he's not the type."* The age, sex, and perceived experience of the physician consulted were also of importance.

"A lot of physicians are male and we are women, so they don't want to ask about something that might be really disturbing and embarrassing."

"I didn't think that he {the 25 year-old doctor} had the experience of life to understand..."

Some women felt it would be easier to talk to a female physician about these sensitive issues. Another woman explained that physicians simply were not a category of professionals with whom she had considered discussing sexual matters:

"When I see my doctor for my disease [diabetes]... it has never even occurred to me to discuss my sex-life - intimacy - with him; it has never entered my head!"

It is worthwhile to note that the latter reflected the attitude of most women. These women did not consider health professionals whom they regularly consulted for their diabetes as sexual counselors.

Whose Initiative?

All groups touched on the issue of who should be responsible for raising the topic of sexual functioning – the female patient or her doctor? Some patients wished that the physician were the one to broach the subject:

"Sometimes I wish he'd {the physician} ask me, 'was there anything else?' when I'm at the door, but I don't take the opportunity myself 'cause I know time is short and all that..."

Others felt that they themselves should initiate the course of action. Overall, there was some degree of insecurity on the part of both women and physicians, as perceived by the participants. Only one woman reported having received a question on her sexual functioning from her GP (*"but he was newly married himself so it could have depended on that"*).

IS CONTRADICTION IN THE MEDICAL ENCOUNTER AVOIDABLE or is it an inherent feature of the system? Is it ever possible for a woman to ask someone for advice without experiencing guilt and shame? Is it ever possible for the physician to ask women about sexuality without fear of being inadequate? Is it the power status and strict social positioning of physicians or women's own self-censure that inhibits communication?

Although the GP might seem self-evident as a sexual counselor, this is probably not the case. Lack of time, fear of intrusion and inadequacy, and age and sex of both patient and physician (214) are difficult barriers to overcome. More research is needed to elucidate with whom different generations of women prefer to discuss sexual issues. In one study, 43% of a group of young adolescents reported that they would feel uncomfortable talking to the family physician if they had a sexually transmitted disease (215). Midwives (216, 217), pharmacists, patient or women organizations, or other forms of peer help might be the preferred instance of women to discuss matters of sexuality, including sexual dysfunction.

6.3 METHODOLOGICAL CONSIDERATIONS

Knowing about Women's Health

According to Oakley, the problem with medical research on women is that “organizing concepts and themes of analysis are selected a priori from the perspective of the researcher, the knower, rather than of the women who are the subjects of analysis” (218). She continues to point out that knowledge on women’s health should be constructed “in the context of their living conditions (...) [in which] they struggle to produce their own identities and their own lives.”

When “attempting to understand the subjective experience of human beings” (127), the preferred framework among feminist scholars has long been the phenomenological approach. “Both the emphasis on subjective experience and the emphasis on illness as a culture-bound category of knowledge are essential to a research enterprise committed to exploring the way in which women make sense of a world largely designed by and for men” (127). In this respect, feminist scholars have underlined the importance and validity of women’s experience as a basis for scientific knowledge.

I would argue that this attitude of respecting the experiences of human subjects and accepting their stories as relevant sources of information is not exclusive for feminist research. It is characteristic of naturalistic inquiry in which the researcher is truly interested in the realities of research subjects, independent of race, sex, and class.

QUALITATIVE INQUIRY FOR STUDYING WOMEN’S HEALTH has resulted in knowledge that, in many ways, questions the premises guiding health care for women (Table VIII.). Before presenting specific examples, however, I would like to make an important point when dealing with women’s health issues.

Women’s health concerns have been subject to extensive advocacy as it was argued that such concerns did not adequate attention in the planning of health care and in the allocation of research funds (219). When conducting research on women’s health issues, it seems especially important to painstakingly keep issues of advocacy and scientific results apart. This point might appear self-evident, but it is easy to confuse the two: advocacy often uses results of research as its basis for argumentation, but no explicit scientific criteria are used to ensure the validity of advocacy statements (e.g., stating both pro and contra facts). In the

following, results are described from scientific, qualitative studies that have contributed to a deeper understanding of the way women make sense of and cope with chronic disease.

Table VII. Qualitative studies on women’s health concerns. Study object and design, mode of analysis, and participant statistics are given.

First author	STUDY OBJECT	STUDY DESIGN <i>ANALYSIS</i>	PARTICIPANTS (females if not otherwise specified)
Allan (148)	Weight-related self-care activities of women	Ethnographic interviews Participant observation	N=37; 19-56 years; 48% partnered; 90% employed
Anders-son (146)	Women’s existential response to diabetes	1-4 semi-structured interviews	N=30; 26<years; DM [†] sample; 67% partnered; 58% employed
Anders-son (145)	Management of illness among immigrant and Canadian women	1-4 semi-structured interviews <i>Feminist epistemology</i>	15 Cantonese and 15 Canadian; >26 years; DM sample 67% partnered; 58% employed
Devine (220)	Women’s nutrition care and social roles	In-depth interviews <i>Comparative analysis</i>	N=36; 32-63 years; partnered; 2/3 employed; 24 child at home
Hunt (143)	Understand women’s (non)compliance	In-depth and telephone interviews (5/person)	N=19; 19-64 years; non-specific symptoms
LeMone (34)	Physical effects of diabetes on sexuality	Semi-structured inter-views <i>Emerging themes</i>	N=20; 28-75 years; DM sample; 15 partnered
Michael (221)	How adults integrate illness into their lives	Phenomenological in-quiry, <i>Colaizzi’s analysis</i>	N=17 (3 men); 21-75 years; DM, CHD [‡] , RA [§] , COPD , asthma
Miller (141)	Food purchase decision-making of women with Type 2 diabetes	Interviews and in-store observations <i>Concept mapping, cluster analysis</i>	N=15, 42-60 years; Type 2 DM sample ; 30% child at home
Nelson (222)	Health practices among workers	Women’s roles interview protocol <i>Domain analysis</i>	N=34; 19-63 years; 59% partnered
Packard (153)	Demands of long-term illness in women	Structured interviews <i>Content analysis four cycles à la Guba</i>	N=115; 28-62 years; DM, non-metastatic breast cancer., FCD [¶] ; 70% married; 54% employed
Perry (223)	Older women’s images of health	Interviews <i>Feminist interpretation, content analysis</i>	N=10; 70-91 years; “functionally independent”
Popay (224)	Mothers’ experience of ill health	In-depth case study of 18 couple households	N=36; 23% long-standing illness; All had dependent children
Price (225)	Physical self-awareness in chronic illness – body listening	Naturalistic design: inter-views, 6-week diary <i>7-step method à Colaizzi</i>	N=18 (6 males); 9 chronically ill with asthma or MS; 25-55 years; 11 married
Shaefer (139)	Understand living with chronic illness	Interviews <i>Phenomenologic reflection</i>	N=6; 30-75 years; OA [#] , SLE ^{**} , FM ^{††} , MS, CHD, dermatitis [*]
Umber-son (131)	Social control & health behavior	In-depth interviews	N=25 (15 male) attorneys; 28-51 years
Wikblad (226)	Identifying strategies for coping with diabetes	Structured interview <i>Phenomenographic analysis</i>	N=31 (+24 men); 24-47 years; Type 1 diabetes; 93% partnered
Young (142)	Women’s health-related behaviors – a time and space analysis	Semi-structured diary sheets, interviews <i>Set of linked codes</i>	N=37; 25-59 years; 49% long-term ill; 76% partnered; 60% employed; 65% child at home

^{*}Multiple sclerosis

[†]Diabetes mellitus

[‡]Coronary heart disease

[§]Rheumatoid arthritis

^{||}Chronic obstructive pulmonary disease

[¶]Fibrocystic breast disease

[#]Osteoarthritis

^{**}Systemic lupus erythematosus

^{††}Fibromyalgia rheumatica

^{*}Skin disease (in this case allergic)

“Qualitative knowledge” about the personal experiences of individuals, the perceptions that guide their behavior, and circumstances that influence their coping often necessitates reconsideration of existing premises that health care for women is based on. One example, presented in Table VIII, is the way older women view their health (223). For them, health apparently extends beyond diagnosis of a chronic disease and functional status: images of health include instead an appreciation of life, experiencing joy, and having energy for daily activities. Being free from sickness and disability does not guarantee well being, whereas depending on others for help does not automatically mean bad health (223). Applying the biomedical definition of being totally free from disease to the health of older women might thus result in miscommunication between the female patient and her caretakers and negatively affect the self-image of the women at worst.

Exploration of gender differences in the perception of common cold symptoms (227) and chronic fatigue (224) is another such example that provided insight into the daily living conditions of men and women that influence their possibilities to react to symptoms. Many women did not consider themselves to have the time for ‘being sick’, whereas others felt that being tired ‘all the time’ was part of their lives as mothers. In another qualitative study on *body listening* men measured bodily functioning in terms of power and strength; in sharp contrast, women asserted their body’s functional capacity in terms of being able to live up to different role obligations (225). Consequently, normalcy was perceived in rather different terms in the two sexes and this obviously may have important implications on how illness is experienced and understood.

CONCLUSIONS

- ***Contrary to our preconceptions and earlier findings in the literature, women did not feel comfortable discussing issues of sexuality with their GPs, although they saw them regularly for their diabetes.***
- ***Personal characteristics, such as age, sex, experience, and attitude of the physician, the specialty considered to be appropriate (GP versus gynecologist), and circumstances (time and privacy) in the primary care setting appeared to significantly influence women’s willingness to discuss sexual matters, if at all, with physicians.***
- ***Sexual care (information, cancer screening, sexual counseling, self-care remedies) for postmenopausal women does not necessarily have to be delivered through the traditional health care system. Midwives, pharmacists, patient or women organizations, or other forms of peer help might be preferred instances by women with sexual dysfunction.***

PART THREE

BORDERLAND REVISITED



1890 107. 2/22 11, 101. *John Langford*

GENERAL DISCUSSION

7.1 THEORETICAL PERSPECTIVES

The Use of Metaphors in Science

This thesis is constructed around a metaphor: Borderland. Therefore, I feel it is appropriate to discuss the use of metaphors in scientific literature. Employing metaphors within research can be contradictory: metaphors are difficult to control and their scientific value and validity can be questioned. "Metaphors can open up new understandings and enhance communications. They can also distort and offend," p. 36 (43).

I would like to argue that, if handled with care, metaphors can be powerful instruments where science and imagination, society and research can meet in the field of medicine.

"Metaphor works by association, by comparing two non-associated entities with each other centering on the ways in which they resemble each other. In doing so, the metaphor shapes perception, identity and experience, going beyond the original association by evoking a host of multiple meanings", p. 55 (11).

Metaphors can thus cover genuine knowledge: the empiric reality as reflected in the researcher's experience, scientific background and imagination. It is probably this extra dimension of metaphors that has led to their use by many researchers in their scientific endeavors whereof I list a couple of examples below.

Barnes, a Norwegian social anthropologist and the founder of social network theory studied a small community by the sea that earned its living from fishing. Barnes was interested in the relations and respective positions of its members and the way the community was organized. It probably seemed close at hand for Barnes to use the metaphor of a fisherman's net to describe the village society, or as he called it, NETwork (137). The knots of the net represented individuals or groups, whereas the ropes between the knots stood for relationships.

Susan Sontag wrote a now classic book on *Illness as metaphor* (229). She uncovers how the public picture of an illness affects the meanings that become associated to it and its sufferers and how illness, in turn, affects social values, fashion and the public morale.

“Twentieth century women’s fashions (with their cult of thinness) are the last stronghold of the metaphors associated with the romanticizing of TB [tuberculosis] in the late eighteenth, early nineteenth centuries. Many of the literary and erotic attitudes known as ‘romantic agony’ derive from tuberculosis and its transformations through metaphor”, p. 29 (229).

In her book on *Medicine as Culture*, Lupton mentions the mechanical, military, and computer science metaphors used to describe disease in both lay and professional discourse (11). Medical professionals e.g. often use metaphors of war when describing their activities in a health care setting. Through the use of metaphors, people with AIDS are implied to suffer not only immune, but also moral deficiency, whereas cancer is depicted as a disruption of the social order of cells, where ‘bad’ cells refuse to ‘co-operate’ and ‘obey’ cell-societal laws (11).

Metaphors are a sensitive instrument to work with. They have a capability of explaining scientific facts and findings based on everyday experiences of lay people. On the other hand, the “multiple meanings” evoked (11) are out of reach for the original communicator of the metaphor. Although this is to a certain extent a goal of using metaphors, I tried to define Borderland in explicit terms (Chapter 1) to provide an initial joint basis for discussion.

7.2 CONCLUSIONS

I

- Based on the experiences of participants, study circles for persons with Type 2 diabetes were found to be a feasible way of learning about self-care and gaining diabetes-specific social support.
- The pharmacist-led group educational program, which functions outside the official health care setting, contributed to fulfilling the goals of the Saint Vincent declaration (103) by “promote[ing] independence, equity, and self-sufficiency” of participants, as evidenced by their responses to the questionnaire and interview items.
- Allocation of tasks, such as practical skills, education and provision of long-term practical and emotional support for self-care, to non-physician health professionals is in accordance with experiences from randomized controlled trials on successful chronic disease management (4).

- Future research should explore the proportion of persons with diabetes that benefit from such an educational approach and the relation between qualitative measures of program success (e.g., positive emotional feedback and practical skills improvement) and long-term successful disease management.

II

- The social control aspect of health education must be born in mind to seek avoid its oppressive features.
- Initial HbA_{1c}, BMI, and loneliness in interaction with treatment influenced success in the diabetes educational program. High initial HbA_{1c} levels were correlated to greater decrease in values, whereas high BMI, marking overweight, interfered with long-term control, but not initial success during the intervention.
- Diet treatment alone seemed to benefit individuals who experience loneliness more than those who do not feel alone, as measured by glycemic outcomes. It is possible that persons on diet therapy who do not feel lonely, but live in a setting with little diabetes-specific support, could benefit from adding oral agents to their regimens. Although our sample size is too small to draw such general conclusions, the interaction between social life, especially its meal-related aspects, and treatment regimen should be given careful thought.

III

- The individual's social network is a source of social support as well as social demands.
- Because of traditional gender roles, obligation profiles associated with meals, cultural expectations on women's physical appearance, and prejudice about the psychological etiology of women's symptoms, the family, paid employment, the social environment, and medical services all represent possible sources of conflict with women's successful diabetes management.
- The social network model could be used in clinical diabetes practice to help women and their caregivers plan appropriate interventions and set up treatment schedules that acknowledge barriers to self-care and comply with women's daily role obligations.

- The newly coined term “Disease Manager Role” implies an active role of the individual in coping with diabetes and underlines the time and energy demanding character of practicing self-care.

IV

- The focus group method had the advantage of gathering many opinions during few sessions and the participants stimulated each other to discuss areas they considered important. A disadvantage might have been that the women were part of a group before the interview with established power relations that could have affected what was said and by whom.
- Sexual dysfunction is common among both menopausal women and those with diabetes and was experienced by nearly half of the women in this study.
- Guilt and shame were recurrent themes, both concerning women’s diabetes and sexual functioning. This guilt and shame, along with social taboo, perceived negative societal attitudes, and women’s own conceptions that their sexual disturbances were caused by “natural aging” powerfully added up to render their sexual dysfunction “invisible.”

V

- Contrary to our preconceptions and earlier findings in the literature, women did not feel comfortable discussing issues of sexuality with their GPs, although they saw them regularly for their diabetes.
- Personal characteristics, such as age, sex, experience, and attitude of the physician, the specialty considered to be appropriate (GP versus gynecologist), and circumstances (time and privacy) in the primary care setting appeared to significantly influence women’s willingness to discuss sexual matters, if at all, with physicians.
- Sexual care (information, cancer screening, sexual counseling, self-care remedies) for postmenopausal women does not necessarily have to be delivered through the traditional health care system. Midwives, pharmacists, patient or women organizations, or other forms of peer help might be preferred instances by women with sexual dysfunction.

7.3 BORDERLAND REVISITED

On my journey to Borderland, I saw the obstacles and contradictions that make communication between Stina, the 'Patient' with Diabetes, and her Doctor, difficult. These roadblocks and conflicting forces include social taboo, gender bias, medical socialization, medicalization, preconceived beliefs, guilt and shame, and power inequity, and are reflected by value judgments, such as compliance, denial, and paternalism. The hierarchy seems shaky and the system, designed for acute health care, increasingly inappropriate for chronic disease management.

My vision for future diabetes care is, therefore, not shifting the 'Patient' from the Doctor's office to already existing agencies of Borderland (motivated persons will find their way to it anyway). It is shifting the whole consultation to neutral Borderland, where the 'Patient' becomes a Disease Manager and the health professional a Medical Advisor. The two meet on equal grounds and set common goals for managing diabetes.

I see a readily accessible center for self-care support in which physicians, nurses, midwives, dietitians, and pharmacist could work as a team with the Disease Manager as an obvious team member. The setting would be of a social nature (23) in which Disease Managers could determine the level of intervention required for the day. Choices could range from sitting and having coffee with one of the Medical Advisors, discussing blood glucose monitoring results that do not seem to make sense, participating in group discussions, sitting and browsing the Internet for new information, or performing pre-scheduled follow-up or other medical examinations in a separate room. When adequate, the Medical Advisors could refer Disease Managers to the traditional health care system for further evaluation or treatment (230).

To ensure continuity (231), the Disease Managers could become enrolled in a (e-)mailing list from which automatic reminders of a follow-up protocol based on shared plans could be sent home to them (4). Disease Managers would carry a "minirecord" (232) that would serve the purpose of continuity of information flow (233). The Disease Managers could write their expectations on the support that they needed for effective self-care along with the shared plan of follow-up and data from self-monitoring or "strange events" in this Diabetes Notebook.

Playrooms with supervision would provide parents with well-needed personal time (142). A senior club, exercise facilities, and a specialized library could be

housed in the same building and volunteer retirees could prepare and sell meals (based on modern diet recommendations – “Good food for all” (234), for take-away or direct consumption for self-cost prices. Cooperation with other agencies of the Borderland, such as the Red Cross, could help attract people with low income, as could services for the unemployed.

Naturally, my vision is biased. My middle-class, academic background, my medical education, and my view of the medical profession, as well as my personal experiences all work to influence my personal vision. However, it is anchored in genuine scientific results and addresses many of the problems encountered by the traditional health care organization in the management of diabetes (4). The vision of Borderland certainly does not solve all of the problems raised and solutions suggested by both users and professionals; however, it does suggest a model of diabetes care based on them.

In fact, examples of certain elements and ideas of Borderland already exist (Chapter 1). Diabetes care and follow-up in Borderland probably does not even cost more than letting Disease Managers occupy primary care time that is usually planned for quick intervention and in any case leaving both the person with diabetes and the Doctor unsatisfied.

Although health care and illness are socially constructed, social systems are not timeless structures, but dynamic realities. Could it be so that time is soon here for chronically ill persons and their Advisors to explore Borderland?

In this thesis I have tried to examine different approaches to systematically support the self-care of persons with Type 2 diabetes, including practical, psychological, and sexual aspects of self-management. In this last section, I summarize and integrate our results and those of others into a future model of diabetes care. I do not know if Borderland will ever become reality. However, it has been my task and pleasure as a researcher to critically examine the circumstances that Sarah, her Diabetes, and the Doctor represent and to propose the possibility of a new alternative.

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