DISSEYRATATION
The lived experience of a chronic illness:
Challenges, Dialogues and Negotiations in
Adherence and Non-adherence

A phenomenological study from the perspective of the person with
diabetes

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Statement:
This dissertation is submitted to the RCN Institute in part fulfilment of the MSc in
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Abstract

The aim of the study was to explore what it is like to have a complex regimen prescribed when living with a chronic disease like diabetes, and what happens in patients’ relationship with healthcare professionals when they do not adhere to the treatment regimen.

The research approach was phenomenology, and the research method unstructured interviews or dialogues. The findings were constructed from 16 dialogues with 11 persons with diabetes, whom were seen as co-researchers. The data analysis was guided by the Vancouver School of Doing Phenomenology.

The findings reveal a dynamic experience, full of conflicts, which can be understood as a constant attempt to live a normal and fulfilling life by balancing the regimen with physical and psychosocial wellbeing. Empirical knowledge is juggled with own experience to gain understanding and place oneself within the context of the disease as well as social context. Strict adherence to the regimen may threaten the person’s need for autonomy. Extreme periods of self-deception give way to a sense of responsibility, defining what constitutes quality of life and struggling to integrate a modified treatment regimen with it. Respecting the disease without letting it dominate one’s life is the key for successful integration. Different desires are in conflict, ‘to do right’ competes with the desire to be normal or give in to temptations that disturb blood-sugar control. Finally, overcoming fear is an important part of the experience; the remote fear of diabetes complications as well as the daily fear of hypoglycaemia and the truth.

The participants in this study described how healthcare professionals use different communication approaches, enabling or disabling, that influence the adherence experience for better or worse.
It is concluded that the lived experience of adherence and non-adherence is a complex, dynamic and multistructured phenomenon, which the dominant biomedical model that tends to guide healthcare professionals’ practices fails to describe sufficiently. It is deeply ethical in nature, it involves two parties, the patient and the healthcare professional, and conflicts may be created in their interaction, between the three ethical principles that guide practice: respect for autonomy, beneficence and justice. The challenges that meet the person with diabetes are dealt with by negotiating with oneself and healthcare professionals can provide support with authentic dialogues, based on respect and trust.

Further studies on the issue of adherence are needed in order to enhance understanding and improve the healthcare services provided for patients who have difficulties with the management of their disease.
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Chapter 1

Introduction

This phenomenological study explores the lived experience of adherence and non-adherence to a prescribed treatment regimen from the perspective of persons with diabetes.

Non-adherent patients are a challenge to healthcare providers. While caring for them, I have experienced an ethical dilemma between respecting patient autonomy and the beneficent duty of nursing. This experience aroused my interest in this important subject, which has been of concern to healthcare providers since ancient times.

1.1 Aim and purpose of the study

The aim of the study is to explore what it is like to have a complex regimen prescribed when living with diabetes, what meaning is put into that experience, and what happens in patients’ relationships with healthcare professionals when they are non-adherent to the treatment regimen.

The purpose of the study is to enhance understanding of the concept of non-adherence, an understanding which is needed in order to avoid discrimination within the healthcare system. It can be argued that non-adherent persons receive suboptimal services because healthcare professionals lack understanding of their behaviour which can be paraphrased as ‘choosing a different pathway from the recommended one’, a choice which sometimes may be the correct one. The patient’s voice is infrequently heard in the adherence literature. This study is a modest attempt to change that.
1.2 Background to the study

Non-adherence is of concern to contemporary healthcare because of its implications for patient health, effective use of resources and assessments of the clinical efficacy of treatments (Playle and Keeley, 1998; World Health Organisation (WHO), 2003). Adherence can be seen as an attitude (with willingness or intention to follow health prescriptions) and behaviour (carrying out prescriptions) (Cameron, 1996).

The term ‘compliance’ was introduced into medicine 30 years ago, and has undergone extensive study since then. Research has predominantly been conducted from the positivist perspective, focusing on etiology and interventions to control non-adherence. It is a controversial, multidimensional and complex issue which raises ethical questions in healthcare, and is further complicated with problems in definition and prevalence measurement. It has been conceptualised as a patient-practitioner interaction, self-care behaviour, a cognitive-motivational process and an ideology, emphasising the professional power of healthcare providers (Kyngäs et al., 2000). Change of terms to emphasise patient autonomy instead of obedience by using the word ‘adherence’ has been suggested (Lutfey and Wishner, 1999). This shift is apparent in today’s literature, although it has been argued that both terms are unacceptable [in diabetes care] because of their underlying assumption that diabetes belongs to healthcare professionals instead of the person with diabetes (Glasgow and Anderson, 1999).

To summarise the discourse in existing literature:

1. Compliance needs to be re-conceptualised, from a linear, controlling activity to a participative endeavour, with the ultimate choice of compliance resting with the patient (Playle & Keeley, 1998; Evangelista, 1999).

2. The patient-professional relationship has become the focus of interest (Kyngäs and Lahdenpera, 2000; WHO, 2003). Redefining the roles of the two parties involved in
adherence is needed; that of the one who prescribes the treatment regimen and the other who adheres to it (Glasgow and Anderson, 1999). Active participation by patients in the treatment regimen is a basic requirement for its success; furthermore, it is defined as the patient’s right under Icelandic law (Alþingi, 1997). A systems approach is required in order to improve adherence (WHO, 2003).

3. An alternative philosophy to the positivist paradigm should guide research, recognising patients’ interpretation of their illness (Ryan, 1994). It should focus on the ways in which individuals give meaning to their own behaviour, based on their beliefs and expectations (Playle and Keeley, 1998; Raphael, 2000).

1.3 Significance to nursing and the researcher’s position

Health promotion is regarded an important aspect of nursing practice, especially with the increasing prevalence of lifestyle-inflicted chronic diseases. Patients are frequently expected to make major changes in their lifestyle in order to control their condition.

Traditionally, the health promotion role is carried out through education, teaching technical skills and providing practical information. In my opinion, nurses (and other healthcare professionals) are neither knowledgeable nor trained in working with non-adherent patients. Exploring how a treatment regimen fits into patients’ lives, and what their concerns are, is rarely addressed properly. The healthcare system, with its schedules and structure, seems at times to be organised around anything but patients’ needs, such as ample time for discussions or continuity of care.

This study explores adherence from a non-positivist perspective, as has been recommended, and is grounded in my viewpoint that the ‘problem’ of non-adherence lies in the discrepancy between the ‘evidence-based best’ or recommended treatment, and the ‘lived best’ or the right choice for each patient at any given time. Health professionals’
role is not necessarily to induce adherence, but to ensure that patients have sufficient information and support to make an informed decision about their treatment regimen. Having done so, they must respect this decision, support patients with changes, if they choose so, but first and foremost support them in their lifelong companionship with the disease. WHO (2003) states that focusing on adherence interventions, and making them more effective, may have a greater impact on the population health than any improvement in specific medical treatments. The importance of adherence should not be underestimated, but promoting it must be done professionally and in collaboration with the patient.

A gap exists in understanding of non-adherence, which can be filled with dialogue between the two parties, patients and providers. Such dialogue can take place within research, and be conveyed to the community of colleagues through research reports.

I hope that this study will encourage healthcare professionals to reflect on their attitudes and communication approach with patients they label ‘non-adherent’. In a wider context, this study may add to the knowledge base of nursing, by describing the complexity of the concept.

1.4 Conclusion
Non-adherence is regarded a problem within the healthcare system, unsolved, in spite of decades of extensive studies. Attention has been called to the fact that the patient’s perspective is rarely addressed in those studies, and a paradigm shift has been recommended, with reconceptualisation of the issue. Hence this study will explore what it is like to have a treatment regimen prescribed for diabetes, and what happens in the relationship between patients and healthcare professionals when non-adherence occurs.
Chapter 2

Literature review

2.1 Introduction

The issue of adherence is always relevant when healthcare professionals prescribe a treatment for health conditions. This study attempts to illuminate what it is like to have such regimen prescribed for diabetes, and what happens in the patient-provider relationship when non-adherence occurs. Diabetes, as a chronic disease, is special in many ways in this context. Its treatment is predominantly self-management; the regimen is complex and requires multi-skills.

In this chapter I will describe the literature search, present key terms in the study and the relevant literature.

2.2 Literature search

Literature search was carried out within different databases under the specialities of ‘health’, ‘social sciences’ and ‘psychology’. Using the terms ‘patient compliance’ and ‘patient adherence’, and then limit it to ‘phenomenology’ and/or ‘qualitative’ yielded few results, and no phenomenological studies similar to mine. The issue of adherence could, however, be found integrated in the literature on lived experience of chronic illness and diabetes. Here I found some qualitative studies, mostly conducted from other perspectives than phenomenology, such as ethnography and grounded theory. Finally, I searched for articles on the concept of ‘patient-provider relationship’ which yielded abundant results.

I include literature on compliance/adherence, from the perspective of both patient and provider. I selected qualitative and combined studies which describe lived experiences of
chronic illness in general and diabetes specifically. Furthermore, I included literature on patient-provider relationship.

This study is guided by a method called the Vancouver School of Doing Phenomenology where the literature search, data collection and data analysis run concurrently as illustrated in Figure 1.

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**Figure 1** Temporal overlapping of literature search, data collection and data analysis in the Vancouver School of Doing Phenomenology (from Halldórsdóttir, 2000, p. 62)
2.3 Key terms

Table 1 presents definitions of key terms as they are used in this dissertation.

- **Adherence** – ‘the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider’ (WHO, 2003, p.3)
- **Compliance** - is used in this dissertation when referring to literature which uses this concept as it is not an exact synonym with ‘adherence’
- **Co-researcher** - a person participating in this study
- **HbAc1 values** - a blood test used to evaluate the long-term adequacy of glycaemic control in people with diabetes. HbAc1 levels reflect total glycaemic exposure during the previous 2-3 months (Gerich, 2005)
- **Healthcare professionals** - registered nurses, physicians and dieticians
- **Independent** - showing a desire for freedom, not subject to control by others
- **Patient** - a person receiving medical treatment
- **Prescribed treatment regimen** - any regimen aimed at treating and/or preventing medical complications of diabetes (dietary restrictions, self-monitoring of blood-glucose, dosing and administering of insulin, appointment-keeping at a diabetes clinic and/or diabetes specialist, and regular foot-care and ophthalmic examinations
- **Principle of Autonomy** - ‘Individuals are entitled to be and do as they see fit, so long as they do not violate the comparable rights of other. No person is to be merely the instrument of another person’s plans; no person is to be treated in a manner that is blind to the plans, desires and values that are the fabric of his or her life and identity……. it is obligatory to leave people alone, unless we have powerful reasons for not doing so’ (Gorovitz, 1982, pp.36-37). Autonomy involves independence, self-care and self-determination (Redman, 2005)
- **Principle of Beneficence** – ‘One ought to do good. Doing good means benefiting people, helping them, acting – out of respect for their interests – in a way that serves their interests’ (Gorovitz, 1982, p. 37).
2.4 Literature review

2.4.1 Chronic diseases and the issue of adherence

With advances in medicine and technology, many formerly acute conditions, such as diabetes, have become chronic diseases. The ‘birth’ of a chronic disease is interestingly described in Feudtner’s (2003) book, based on diabetic patients’ experiences, in their own words, describing the transformation of diabetes with the discovery of insulin in 1921. Managing the illness became a day-to-day task, patients and physicians had to find a strategy to organise those daily efforts, and, finally, the question arose: Whose responsibility was it to manage the illness? – still a core question in the debate about adherence.

Adherence by definition involves two parties, those who prescribe and those who adhere to prescription, the healthcare professional and the patient. Research on adherence has, however, predominantly been patient-oriented (although not exploring the patient’s perspective), focusing on etiological factors, measurements and interventions to ‘cure the problem’. In spite of extensive studies, adherence rates are not improving. Poor adherence is today deemed ‘a worldwide problem of striking magnitude’ (WHO, 2003), with adherence in developed countries among chronically-ill patients averaging only 50%.

Other aspects of adherence than the patient have been largely ignored in research and this has attracted criticism. The WHO report (2003) which summarises the existing knowledge of adherence conceptualises adherence as a multidimensional phenomenon, determined by five interacting dimensions (see Figure 2), where the patient is but one. Effective interventions have been designed and tested, but adherence may not be improving because the interventions are not multifocused (WHO, 2003).
This orientation in research may reflect the dominant ideology, which views non-adherence as irrational and deviant individual behaviour (Playle and Keeley, 1998). Others argue that adherence is a socially constructed phenomenon (Fineman, 1991), and reflects paternalism on the part of healthcare professionals (Bournes, 2000), from this standpoint it would be feasible to study adherence further from the critical-theory perspective.

In summary: two perspectives are in conflict, that of patient and healthcare professional. They concern who is responsible for the disease management, who is the expert, who should decide the treatment regimen, and how to prioritise and manage it.

2.4.2 The patient’s perspective
Studies that focus on adherence from the patient’s perspective are rare (Wellard, 1998), although such research has been called for, based on an alternative epistemology to the positivist (Playle and Keeley, 1998). Managing diabetes has been identified as the greatest challenge of living with the disease (Callaghan and Williams, 1994), and the
issue of adherence has been analysed as one construct of chronic illness (Price, 1996; Wellard, 1998). Few qualitative studies focus exclusively on adherence, but it is integrated in studies on the lived experience of chronic illness. The insider perspective in chronic illness research represents patients as analysts of their illness experience, active agents in attaining a desired outcome, and experts in self-care (Thorne and Paterson, 1998). Managing the disease is developed into an ‘illness career’ where the individual learns to respond to changes in health, relationships with healthcare professionals and psychosocial aspects of the disease (Price, 1996). The terms ‘self-care’ (Sigurðardóttir, 2005), ‘self-management’ (Koch et al., 2004; Kralik et al., 2004) and ‘decision making’ (Paterson and Sloan, 1994; Paterson et al., 2001; Thorne et al., 2003) are appearing increasingly in the nursing literature, reflecting a shift in research perspectives towards valuing and recognising the patient’s responsibility and autonomous participation in his/her own care. Thorne and Paterson (1998), however, warn against idealising the chronically-ill person as strong, powerful and competent, thereby ignoring the continuing need many people have for professional expertise, support and help.

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

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

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

Achieving ‘health within illness’ is a newly recognised phenomenon under study (Lindsay, 1996; Whittemore and Roy, 2002) which involves, again, integration of physiological and psychosocial aspects of daily life. This transformational experience achieved by some has been described by Paterson et al. (1999). Whittemore and Roy (2002) have developed a theory on the process of adaptation to diabetes, synthesised on the concepts of ‘integration’, ‘self-management' and ‘health-within-illness,’ along with their nursing theory of chronic illness.
Three qualitative studies were found on the compliance issue from the chronically ill patient’s perspective. The oldest one (Conrad, 1985), on people with epilepsy, revealed how regulating medication represents an attempt to assert control over the condition and modification of the regimen may be due to negative side-effects, need for independence, destigmatization or as a proactive behaviour for special social circumstances. Conrad concludes that the issue is more one of self-regulation than compliance. Thorne (1990) conducted a grounded-theory inquiry into the meaning of non-compliance. The purpose of non-compliant behaviour was seen as twofold: self-protection and maintaining a healthcare relationship. Non-compliance was a strategic means to preserve quality of life, and protect oneself from what the participants viewed as inappropriate clinical decisions. Diminished compliance was interpreted as a product of their taking increasing responsibility for own health; increased confidence entailed diminished confidence in professional expertise. Roberson (1992), in a qualitative (unspecified) study interviewed rural African-Americans. Her findings portray individuals who differ from healthcare professionals in their interpretation of compliance and goal-setting, who develop strategies of self-management which suit their lifestyle, belief patterns and personal priorities, but may leave them labelled as noncompliant by healthcare professionals.

Several nursing studies have been conducted in Finland on compliance/adherence in chronic illness (Kyngäs and Lahdenpera, 1999; Kyngäs, 2000; Toljamo and Hentinen, 2001a, 2001b). These are mainly descriptive studies (questionnaires and/or interviews) and many focus on adolescents. Here I found the only theoretical model of compliance (Kyngäs, 1999), relevant to my study although based on adolescents’ experience and the author’s own definition of compliance (see Figure 3). Factors that improve compliance are motivation, the results of care, a sense of normality and adequate energy and will-power for care. Support and fear were also found to affect adherence.
Support has been found to affect adherence, and is an important part of the lived experience of chronic illness (Olsen and Sutton, 1998; Toljamo and Hentinen, 2001b). Support can be informal or formal, but family and friends play an important role, as do healthcare professionals. Structured and formal peer-support has been found to be helpful (MacPherson et al., 2004). An interesting study on compliance and support was conducted by Kyngäs et al. (1998). In a combined, descriptive study they explored adolescents’ perception of physicians, nurses, parents and friends as a help or hindrance in compliance. Their findings reveal how accepting, responsive and person-centred relationships provide optimal conditions for good adherence.

More intervention studies have been called for (Dunbar-Jacob and Mortimer-Stephens, 2001), involving multifocused interventions aimed at improving adherence. An
interesting and different social intervention study, to improve medication adherence, used empowerment home education and nursing assessment with AIDS patients (Williams et al., 2005) successfully and is proposed as a feasible addition to the more traditional interventions based on socio-psychological theories of individual behaviour.

In recent nursing literature, the terms compliance/non-compliance are hardly used, and adherence/non-adherence rarely and then defined differently (Kyngäs, 1999). Instead, ‘self-care’ and ‘self-management’ are more evident terms indicating a paradigm shift in research and concept use.

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

2.4.3 The healthcare professional’s perspective

In diabetes, healthcare professionals design a treatment regimen in order to achieve strict glycaemic control. Their prescriptions are evidence-based, and aim to prevent and/or delay diabetes complications, thus improving the patient’s quality of life and health outcomes, and reducing healthcare costs (Bergenstal et al., 2005; Blonde and Karter, 2005; Davidson, 2005; Gerich, 2005; Renard, 2005). Healthcare professionals are trained within the positivist biomedical model which focuses on diseases, problem-solving and evidence-based practice. Promoting adherence within this model is perceived a professional and ethical duty (Wens et al., 2005), where non-compliant behaviour can not be accepted. Practitioners choose various stances in their efforts to increase adherence, such as ‘educators, detectives, negotiators, salesmen, cheerleaders and policemen’ (Lutfey, 2005). Healthcare professionals used to exert such power over patients that they
had authority to use (almost) all means to bring about obedience, sometimes successfully. This approach may, however result in a disabling relationship where blame, shame, anger and frustration are expressed on both sides. And it does not improve adherence rates. Patients in such relationships have described how they covertly care for themselves by using own helpful strategies (Lindsey, 1997) but in encounters with healthcare professionals they may falsify records, lie about their adherence, use silence in communication, or ceasing to attend the clinic.

Traditional assumptions about to whom diabetes belongs, who is responsible for the management and who the expert is, are being challenged as well. There are those who call for more radical shift in perspectives, with consequent changes in use of terms. Thus Anderson and Funnell (2000) state that both compliance and adherence are dysfunctional concepts in diabetes care, as diabetes belongs to the person with diabetes, and they call for an empowerment/collaborative approach with new vision of diabetes education and redefinition of the roles of educators and patients.

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

Medical anthropologists have approached the issue of non-compliance, and Hunt and Arar (2001) developed an interesting analytical framework which portrays the complexity of similarities and differences between providers’ and patients’ perspectives in the management of chronic illness. It illuminates how simplistic and inaccurate it is to label patients as non-compliant/non-adherent because, for most people, their behaviour represent series of microdecisions which aim at balancing their treatment behaviour against the multiple competing non-medical factors in their lives.

2.5 Summary

Two perspectives dominate the discourse on adherence. One focuses on etiology, measurement and intervention strategies to solve the problem, mainly patient-focused and based within social psychological theories of individual behaviour. The other challenges this view and calls for a broader exploration of the subject, with patients as equal participants, re-evaluating the meaning of adherence, from the individual as well as social perspective. The World Health Organisation has embraced both perspectives by calling for a systems approach in addressing adherence issues in chronic illness. Qualitative studies on adherence are rare and seldom focus on the patient’s perspective, and there is a need for more intervention studies.
Chapter 3
Research design: methodology and methods

3.1 Introduction
A literature review on adherence has been presented. This chapter will describe the study’s underlying philosophical assumptions and methodological approach. Furthermore, qualitative issues in qualitative research will be discussed, concluding with a brief summary of ethics in such research.

3.2 Paradigm: research perspective and philosophy
Any process of formal inquiry is said to be guided by a research paradigm, a set of basic beliefs representing the holders’ (or researchers’) worldview (Guba and Lincoln, 1994). It defines the nature of the world and the relationship between individuals and the surrounding world. The beliefs can only be accepted on faith and cannot be proved. Embedded within the paradigm, or philosophy, is ontology (defining the form and nature of reality) and epistemology (defining what can be known and how it can be known) guiding the chosen methodology (Crotty, 1998). The constructivist paradigm (Guba and Lincoln, 1994) is the guiding philosophy of my study.

The constructivist paradigm emerged in contradistinction to positivism, in an attempt to understand and explain human and social reality (Crotty, 1998). It adopts relativist ontology, a transactional and subjectivist epistemology (created findings) and a hermeneutic, dialectical methodology, as opposed to the realistic ontology of positivism, dualist/objectivist epistemology and experimental/manipulative methodology (Guba and Lincoln, 1994). Positivism has dominated research on compliance but its inability to focus on the lived experience of people calls for a paradigm shift in compliance research.
in order to enhance our understanding of the concept (Playle and Keeley, 1998; Raphael, 2000).

3.2.1 Ontology
The ontology of constructivism assumes relative and constructed realities (Guba and Lincoln, 1994), apprehendable as multiple, intangible mental constructions, based on experience and social context. They are local and specific in nature, and dependent for their form and content on the individual persons or groups holding those constructions. Constructions are alterable, as are their associated realities. There is an emphasis on the world of experience as it is lived by human beings. No unique real world pre-exists, independent of human mental activity and human symbolic language (Schwandt, 1994). Instead, multiple realities are assumed, interrelated and context-determined. The world is in a dynamic state of flux, and truth is found in changing patterns. Therefore, most basic human truths are only accessible through inner subjectivity (Haase and Myers, 1988; Thorne, 1994). This radical relativism emphasises perspectives where meaning lies in the individual transaction with a situation (Annells, 1996).

3.2.2 Epistemology
The constructivist epistemology assumes that no objective truth is waiting to be discovered. Instead, truth or meaning comes into existence in and from our engagement with the realities of our world. The world and the objects in the world are indeterminate. They may be pregnant with meaning, but the meaning only emerges when consciousness engages with it. Constructivism claims that meaning is constructed by human beings as they engage with the world they are interpreting (Crotty, 1998).

Knowledge is constructed between interactions among human beings and their world and developed and transmitted within an essentially social context (Crotty, 1998). Similarly,
in the research process, the inquirer and the subject of inquiry together create the findings or knowledge.

3.3 Methodology and philosophical underpinnings

3.3.1 Phenomenology

Phenomenology is a philosophy and a research approach (Omery, 1983) within the constructivist paradigm (Guba and Lincoln, 1994). The founder of phenomenology, Husserl (1859-1938), introduced the concepts of subjectivity and ‘lifeworld’ and emphasised that philosophy must begin with the phenomena (things) themselves (Cohen, 1987; Fjelland and Gjengedal, 1994). Heidegger (1889-1976) took phenomenological philosophy further and moved the focus from epistemology to ontology. His philosophy was mainly concerned with existential ontology (Cohen, 1987), describing the concept of a person and Being-in-the-World (Leonard, 1994).

Two distinctive schools of thought exist within the methodology, interpretivist/descriptive (Husserlian) and constructivist/hermeneutic (Heideggerian) phenomenology (Cohen and Omery, 1994). Their common goal is to understand the complex world of lived experience, the meaning of phenomena, from the point of view of those living it. Understanding is gained through interpretation of the experience. The two schools differ on ontological and epistemological issues, defining different aims and purposes of human inquiry and how understanding is gained (Schwandt, 1994).

3.3.2 Hermeneutic phenomenology

Hermeneutics is the theory and practice of interpretation concerned with the nature of understanding (Van Maanen, 1997).

The hermeneutic phenomenological school of thought focuses on existential ontology, on questions of experiencing and how understanding takes place (Ray, 1994). It postulates
that we are introduced to a shared world of meaning that is provided to us by our socio-
historical culture, shaping our thinking and behaviour throughout our lives and expressed
through language (Plager, 1994; Crotty, 1998). Heidegger defined his philosophy as
hermeneutic because he saw it as a methodology for his ontological quest of uncovering
what it means to be a human being (Plager, 1994). Living in the meaningful world that
we understand allows us to make sense of what we are doing, but this familiarity can also
make us lose sight of the understanding; we take it for granted and stop noticing it. The
hidden meanings of everyday life are the focus of hermeneutic phenomenology (Plager,
1994).

Hermeneutic phenomenology emphasises the uniqueness of experience and phenomena
(Corben, 1999). The purpose of inquiry is understanding, not theory-building. Therefore,
the data can only be viewed as ‘illuminations of experience’; they stand alone as a
testimony of the lived experience of those individuals. Analysing the data is the process
where understanding occurs, through the ‘fusion of horizons’ (Gadamer, 1994) of the
researcher (created by his/her preconceptions about the phenomenon) and the participant
(created by his/her experience of the phenomenon). This is further illustrated and
explained in Figure 4.
Understanding is a ‘circular’ phenomenon. It takes place within the hermeneutic circle, where parts are considered within a whole and the whole is only understandable in respect of its constituent parts (Bleicher, 1980). We enter the hermeneutic circle with the two horizons, and interpretation occurs through their fusion (Koch, 1996). Interpretation takes place throughout the research process. The co-researcher interprets the experience, the researcher re-interprets that interpretation, influenced by his/her interpretation of the world (prejudices). The researcher analyses the text hermeneutically in the circular, threefold movement of whole/parts/whole. The text is read, to gain a sense of it as a whole (overall theme of the experience). Then the parts of the whole are identified, and here the paradox of uniqueness and sameness appears. What constitutes the unique experience for each person has ‘sameness’ to the experience of others (Dahlberg and Drew, 1997). These shared experiences construct the themes, the structures of experience (Van Maanen, 1997). The third step of the analysis, closing the circle, is returning to the whole which now has gained new meaning, the whole always being more than the sum of its parts. Understanding has taken place. The challenge awaiting the researcher is to convey the story in writing in such a way that others can understand it.

Figure 4   Understanding: The hermeneutic circle

3.4 Methods used for sampling, data collection and analysis

The methods for sampling, data collection and analysis are guided by the ‘Vancouver School of Doing Phenomenology’ (Halldórsdóttir, 2000). The method, influenced by Spiegelberg, Ricoeur and Schwandt, stands for moderate realist ontology, a transactional epistemology and a hermeneutic, dialectical methodology. The research process involves the cyclic movement between seven stages (Figure 5), and the hermeneutic circle (Figure 4) to grasp the meaning of a phenomenon.
Reflection is a core idea in the school, entered again and again in the research process. The researcher enters each stage repeatedly throughout the research process while ‘doing’ the twelve steps of the method (Table 2), producing a multi-voiced reconstruction of the lived experience under study.

1. Selecting dialogue partners (the sample)
2. First, there is silence (before entering a dialogue)
3. Participating in a dialogue (data collection)
4. Sharpened awareness of words (data analysis)
5. Beginning consideration of essences (coding)
6. Constructing the essential structure of the phenomenon for each case (individual case construction).
7. Verifying the single case construction with the co-researcher.
8. Constructing the essential structure of the phenomenon from all the cases (metasynthesis of all the different case constructions).
9. Comparing the essential structure with the data.
10. Identifying the over-riding theme which describes the phenomenon (interpreting the meaning of the phenomenon).
11. Verifying the essential structure (the findings) with some research participants
12. Writing up the findings

Table 2 The 12 basic steps of the Vancouver School of Doing Phenomenology (from Halldórsdóttir, 2000, p.57).
3.4.1 Sampling

In a phenomenological study two principal criteria exist for eligibility: to have experienced the phenomenon, and willingness to talk about that experience to an interviewer (Thomas and Pollio, 2002). This type of sample is purposeful (Morse, 1991), participant selection is based on the study’s need to ensure authentic, useful and rich data which represent the phenomenon.

The sample size is determined by the data collected, the research question and the researcher’s abilities, but purposeful samples tend to be small and cannot be regarded as representative of the population. The sample should also be heterogeneous, including individuals that have both typical and atypical experience of the phenomenon (have been adherent and/or non-adherent to the treatment regimen) and resemble the study population. Furthermore, it is preferable to include only those who are not in the middle of the experience under study (Halldórsdóttir, 2000).

3.4.2 Data collection

The data consist of the participant’s description of the experience of adherence and non-adherence, expressed in his/her own words in a dialogue with the researcher. It is a co-creation, a product of the interaction between participant and researcher. As hermeneutic phenomenology aims at gaining a deep understanding of an unknown phenomenon, the interview must be unstructured, open, and encourage the participant to speak freely (Kvale, 1996).

3.4.3 Data analysis

Data analysis and data gathering are done simultaneously. The emerging themes determine when enough data have been gathered; when new themes cease to appear, saturation is achieved and additional data are not required.
3.5 Trustworthiness, rigour of the study

The quality of the qualitative inquiry has been a cause for ongoing debate. The positivist concepts of internal and external validity and reliability were replaced by Lincoln and Guba in 1985 with the parallel terms of credibility, transferability and dependability, and these have been widely used since in evaluation of qualitative research (Emden and Sandelowski, 1998).

A trustworthy study is truthful and consistent as well as useful to other people. Trustworthiness depends on how the research process has been carried out and how closely the findings represent the experiences of the participants (Clayton and Thorne, 2000). Certain methods can be used to enhance trustworthiness (Leininger, 1994; Slevin and Sines, 1999; Sandelowski and Barroso, 2003), but they must be congruent with the philosophical underpinnings of the study.

The truthfulness (credibility) and consistency (dependability) of the research findings can be evaluated by the audit (or decision) trail. A reflective journal, kept throughout the research process and attached to the report, provides the reader with evidence from which the decision-making trail can be audited (Clayton and Thorne, 2000). Reflexivity is an attempt to invite the reader to travel into the context-bound world of the participant and researcher, and decide if the text is believable or not (Koch and Harrington, 1998).

Truthfulness is established when the participant’s perspectives have been clearly and accurately presented, and confirmed when the situation is recognised by others. To accomplish this, the researcher must acknowledge his/her own influence on the data, make his/her own presuppositions explicit in a reflective journal, by continual self-critique and self-appraisal (Koch and Harrington, 1998), and describe what is going on during the research. Checking and rechecking interpretations, eliciting co-researchers’
feedback, and peer evaluation are other methods to ensure truthfulness (Halldórsdóttir, 2000; Priest, 2002).

Consistency relies upon the fit between the methodology and the philosophical basis and can, again, be made explicit through the audit trail, where the research process, the selection of methods and analysing processes are described (Annells, 1999; Koch, 1994).

The applicability of a study is determined by how it fits into a given context outside the research situation. Again, the audit trail enables the reader to judge the usefulness of the findings, if the situation, time and participants are described thoroughly.

3.6 Ethical considerations

Ethical concern about privacy, confidentiality and anonymity can easily arise in phenomenological inquiry, when people reveal their personal experiences (Guba and Lincoln, 1994). Human rights must be safeguarded in research, and ethical codes and principles provide guidelines, but every researcher must evaluate these for him/herself (Punch, 1994) by using ‘reflective ethical inquiry’, constant self-questioning through the research process regarding the possible consequences of intervening in other people’s lives (Kylma et al., 1999). Contemporary guidelines emphasise informed consent as a prerequisite for conducting such studies with humans, and require researchers to make arrangements in regard to possible harm entailed by participation in the study.

The Vancouver School represents an ethically important viewpoint as it emphasises equality between the researcher and the participant, who is regarded a co-researcher. The aim is not to research the patient, but to engage in a dialogue with a person who has an experience I am interested in and want to understand, and whom I will regard as a truth-telling co-researcher (Halldórsdóttir, 2000).
Confidentiality implies that any personal data that could lead to the identification of the participant will not be reported (Kvale, 1996). This can be avoided by giving each participant a pseudonym in the research report and not disclosing any information which could violate confidentiality. Special measures are needed in small societies like Iceland, where the risk of this should not be underestimated. Recorded data and all information on participants must be kept confidential, secured in places inaccessible to others, and ultimately destroyed.

3.7 Summary

Phenomenology as a philosophy and methodology was described in this chapter, along with the guiding method of this study, the Vancouver School of Doing Phenomenology. Issues regarding the trustworthiness of qualitative studies and important ethical concerns were discussed. In the next chapter I will describe how I conducted data collection and analysis.
Chapter 4

Data collection and analysis

4.1 Introduction

The study’s underlying philosophical assumptions, methodology and methods have been introduced. I will now describe how data collection and analysis were carried out.

4.2 Access and permission for data collection

The study’s population comprises people with diabetes who have experience of adhering and/or not adhering to their prescribed treatment regimen. Participation in the study was limited to Icelandic-speaking adult diabetics, diagnosed at least three years before, who use insulin injections as part of their treatment regimen. I used this criterion in order to find participants who had had time to adjust to the treatment regimen, and their use of insulin makes the regimen clear, although complex.

Access to participants was gained by advertising (Appendix 1) for participants on the Diabetic Association website and its free newsletter. Seven people were recruited this way. The other four were contacted on the suggestion of nursing colleagues, and were chosen from a group of people contacted in this way. An informed-consent form (see Appendix 2) in duplicate was sent by post to those who were willing to consider participation in the study. Enclosed was a stamped envelope. Those who returned a signed copy were considered voluntary participants.

Formal clearance for conducting the study was sought from the National Bioethics Committee of Iceland (Appendix 3), and the Icelandic Data Protection Commission was notified about the study (Appendix 4).
4.3 The pilot interview

A formal pilot interview was not conducted for this study. However, as a part of the Research Methods course previously undertaken I prepared, recorded, transcribed and analysed (using the Vancouver School of Doing Phenomenology) a dialogue about adherence with a person with chronic renal failure, who also has a complex treatment regimen to adhere to. This valuable experience gave me an opportunity to reflect on my own prejudgements about adherence and my interviewing skills, and try out the analysing process.

4.4 Data collection and analysis

Data collection was carried out by in-depth, unstructured interviews or dialogues, a total of 16 dialogues with 11 persons. Each dialogue took 60-150 minutes, yielding a total of 27 hours of recorded data. In transcription each person was given a pseudonym. The data collection was conducted from March to June 2005 (15 dialogues), and in September 2005.

When the co-researchers had signed and returned the consent form, we arranged to meet at a place of their choice, usually at their homes. I met one person in a hospital, one at the person’s workplace, and two in an apartment available to me. I met five of the co-researchers twice, and the others once.

I will now describe how the data were collected and analysed (guided by the Vancouver School as described theoretically in Chapter 3).

4.4.1 Selecting dialogue partners – sampling

Selecting dialogue partners, (hereafter called co-researchers) was an ongoing process. I sought people who had experience of adherence and/or non-adherence and were willing
to share that experience. As some volunteered to participate I did not know much about them before our meeting, and had therefore no indication of their adherence or their ‘quality’ as co-researchers beforehand. Most of them turned out to be very reflective, willing and organised in describing their experience.

The co-researchers fit the criteria of the Vancouver School for sampling (see 3.4.1). Half of the group had diabetic complications; one person had DM type 2, but fulfilled the criteria of using insulin as a part of treatment. Their characteristics are presented in Table 3.

The Vancouver School recommends that co-researchers not be in the middle of the experience under study. Living with diabetes and adhering to the treatment regimen is an ongoing experience and does not end. Non-adherence was the focus of the study, and the dialogues revealed that my co-researchers had all experienced periods of both adherence and non-adherence, while the duration and intensity varied. For some, non-adherence was a problem of the past, for others it was a continuous struggle. They emphasised, however, that they would never have volunteered to participate in a study like this during a non-adherent period, and hence they were arguably not in the middle of the experience at the time of the interview.

Few had been strictly adherent most of their adult life. None was completely non-adherent at the time of the study. I encountered different viewpoints about this experience.
# Table 3  Characteristics of the co-researchers

The Vancouver School recommends 5-15 cases in phenomenological studies, and preferably two dialogues with each participant. I met five of the co-researchers twice, and the others once. I had difficulties with transcribing one dialogue because of technical problems in recording. I listened to it more often instead and could use it when verifying my findings. I did not meet the other six for the second time because they either were not

<table>
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<td></td>
</tr>
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</tr>
<tr>
<td>Male</td>
<td></td>
<td>5</td>
</tr>
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<td>Nationality and race</td>
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</tr>
<tr>
<td>Age</td>
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<td></td>
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<tr>
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<tr>
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<td>48 years</td>
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<td>Years living with diabetes</td>
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<tr>
<td>Years range</td>
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<td>5-60 years</td>
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<tr>
<td>Mean years</td>
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<td>8</td>
</tr>
<tr>
<td>DM 1 as an adult</td>
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<td>2</td>
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<td>5</td>
</tr>
<tr>
<td>Without complications</td>
<td></td>
<td>6</td>
</tr>
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</table>
giving very rich data, lived very far away or saturation point of the study was achieved after the first meeting.

### 4.4.2 Collection and analysis of data

The process of data collection and analysis, steps 2-11 (see Table 2) is described in details below.

#### Step 2  Silence – before entering a dialogue
I prepared myself by resting and relaxing, emptying my mind and focusing on the task ahead. I planned how to enter the dialogue and how I would deal with situations that might arise, such as how to probe and guide the dialogue to the experience of adherence. As the study progressed this became easier and I found how my confidence increased. I kept a reflexive journal and I wrote down my thoughts after each dialogue.

#### Step 3  Participating in a dialogue – data collection
Achieving rapport with my co-researchers was important in this step. As they were all quite enthusiastic it did not prove problematic. I focused on being attentive, interested and relaxed, considering what I had learned about interviewing in qualitative research. It surprised me how curiously and perhaps naively, I entered the dialogues. This may be due to the fact that my former encounters with diabetic patients have primarily been in the high-speed hospital environment, where their life with diabetes has not been our main topic of discussion. I initiated the dialogues with broad questions about the initial diagnosis and treatment, the experience of adherence and non-adherence, what it was like and how they felt. I used probing to ask further questions, and as new themes and experiences unfolded I used these in subsequent dialogues as probing questions. Sometimes I had difficulties guiding the dialogue to the issue of adherence, the meaning of that experience, instead of only stories about events or situations. I compared the experiences of one co-researcher with another in search for validation of data. Through this interaction the construction of the lived experience was created.
Step 4    Sharpened awareness of words (data analysis) and beginning consideration of essences (coding)

After having recorded the dialogues I transcribed them verbatim within a few days, then printed them and started reading. First straight through, like a story, then again and again to gain a sense of the experience. I listened to the recordings again to gain a better feeling of how things were said. The Vancouver School emphasises ‘living with the data,’ ‘immersing’ oneself in the data with an open mind and attentiveness. Most of the dialogues took place during a 10-week period in the spring of 2005; I used the following weeks to ‘live with the data,’ as my schedule was interrupted with work and holidays, returning to the data regularly, but without formal analysis. This ample time should have prevented ‘premature closure’ (Lincoln and Guba, 1985) in the analysis process and increased the quality of the study. I entered step 5 gradually, identifying key statements and according themes and coding them. I used the analysed themes in probing during the second interviews, and the later dialogues of the first round.

Step 5    Constructing the essential structure of the phenomenon for each case

When each case had been analysed I made an analytical framework, grouping key statements and themes together in order to find the essential structure of the phenomenon for that particular individual. I used the cyclic process of silence, reflection, identification, selection, interpretation, construction and verification as described in Figure 5, and provided myself with privacy and plenty of time for this task.

Step 6    Verifying each case construction with the relevant co-researcher

I conducted this step in my second meeting with those I met twice, using the second encounter as a verification of my interpretation of the first. I made a drawing, representing the key themes of the experiences of adherence, which I presented to my co-researchers. I phoned all but one of those I had met once and asked them to verify (or not) the analytical framework I had constructed from the dialogue and then sent them. A positive verification came from all of those who replied either by e-mail or by phone.

Step 7    Constructing the essential structure of the phenomenon from all the cases

I compared all the dialogues, seeking similarities and differences. This is the process of understanding the phenomenon, using the hermeneutic circle described in Chapter 3. I was challenged here with the question: How can I isolate the experience of adherence from the overall experience of living with diabetes?
Step 8  Comparing the essential structure of the phenomenon with the data
I compared my findings with the raw data, in order to find a ‘proof’ in each case for each theme and/or subtheme. I could confirm all the main themes with each co-researcher, and each subtheme with some co-researchers.

Step 9  Identifying the over-riding theme which describes the phenomenon
Although several concepts seemed fit to describe the phenomenon during the analysis phase it was not until the end of the writing up process that the appropriate theme was found, with the assistance of my supervisor. The experience of adherence is characterised by endless challenges that are met by negotiating with oneself, and in dialogues with oneself and healthcare professionals.

Step 10  Verifying the essential structure of the phenomenon with some of the co-researchers
The main themes were analysed from a relatively early stage, and constructed most of the analytical frameworks presented to the co-researchers in step 7, and verified by them. In order to further strengthen the trustworthiness of the study, I decided to seek verification from non-participants as well. One person with diabetes, one who struggles with obesity (adhering to diet/exercise recommendations) and one smoker (adhering to smoking cessation) recognised the main themes as similar to their experience of adherence.

Step 11  Writing up the findings
was done with the aim of telling my co-researchers’ stories, using their own words in order to present the lived experience of adherence/non-adherence.

Table 4  Data collection and analysis

4.5 Ethical concerns
The main ethical issues that concerned me were how to maintain confidentiality and anonymity of the co-researchers.
The first step was to design information and consent forms which met the rights and needs of the participants and declared my obligation to secure confidentiality and anonymity (Appendix 2).

Privacy was secured by allowing the co-researchers to choose a place for our meetings, and I asked them to plan time and place with privacy and freedom from interruption in mind.

I sought to preserve confidentiality by omitting my co-researchers’ occupation, age and habitation in the findings, as these might imply their identity and make them recognisable to healthcare professionals. The small population of Iceland (300,000) can present a problem with securing anonymity in a study like this, concerned with individuals with certain diseases and the health professionals caring for them, and this should not be underestimated. I believe, however, that participants’ anonymity was preserved in my findings.

I anticipated problems if colleagues who assisted me in finding participants recognised those in the study. I tried to eliminate this risk by recruiting as many participants as possible through advertisements and, when they were recruited via colleagues, by obtaining more people than necessary and choosing participants from that group.

Furthermore, I arranged an access to a nurse who could provide support for my co-researchers, if they felt a need for such after our meeting (see Appendix 5).

All relevant information on participants and research data were kept in a locked place, accessible to me alone. The recordings will be destroyed after the submission of the dissertation.
4.6 Summary

The study’s data collection and analysis process has been described, along with problems that arose and ethical concerns that had to be addressed. In the next chapter I will present the findings of the study.
Chapter 5

Findings

5.1 Introduction

In this chapter I present the findings of the study. I start with a phenomenological description which summarises the lived experience of adherence from the perspective of the diabetic person. Next I present the themes and subthemes of this experience, and conclude with findings from the question: ‘What happens in the relationship between healthcare professionals and the diabetic person when the latter is non-adherent to the prescribed treatment regimen?’

5.2 A phenomenological description

5.2.1 The experience of adherence can be understood as a constant attempt to live a normal daily life through balancing the prescribed regimen with physical and psychosocial wellbeing.

This experience is dynamic in nature, changing from one time to another, and the effects of its constructs vary. It is characterised by juggling information and empirical knowledge with one’s own experience, in an attempt to gain understanding and place oneself within the context of the disease and social context. Body-listening is an important part of this process, the ‘guiding light’ in an attempt to find a comfortable and safe condition.

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

When adherence is unmanageable, dialogue and negotiations with oneself take place, with the desire to do right competing with the wish for normality and giving in to temptations, either ‘good’ or ‘bad,’ which may disturb blood-glucose control.

The lived experience of adherence involves fear and the attempt to fight it. There is fear of the consequences of non-adherence, often felt as quite a remote fear, unlike the fear of hypoglycaemia, which may become the daily companion of adherence. This scrupulous precision, being low enough but not too low, is a constant stressful and uncomfortable feeling.

5.2.2 Encounters with healthcare professionals

After living with diabetes for a time, the diabetic person comes to the clinic in search of updated information, screening for complications and long-term blood-sugar values. Living with diabetes is mainly perceived as a private matter, and discussions with doctors or other healthcare professionals about this experience are not very common. There are no expectations of much more, only of practical service, courtesy
and respect. Encounters with healthcare professionals are controversial in nature, and dependent on time, age, individual doctors and the diabetic person. The non-adherent persons have met patronising and indifferent doctors, but also caring, interested, and accepting ones. Encounters with the former could lead to covert behaviour, non-attendance for check-ups, frustration and anger, falsification of records and silent communication. The latter provided a feeling of support and security and willingness to return to the clinic.

5.3 Main themes: the lived experience of adherence

Most of the co-researchers had personal experience of both adhering and not adhering to the treatment regimen, to the extent of being reprimanded by their doctor. A few of them had been adhering strictly to their regime for decades, with the feedback of having very acceptable HbAc1. However, their blood-glucose control was not always optimal.

Table 5 presents the analytical framework of the lived experience of adherence, with main themes and subthemes. Four themes were analysed and each theme was recognised by the co-researchers. The themes interact with each other and the intensity of each factor differs, between persons and within the same person at different times. The experience of paradox between freedom and constraint represents common conflicts within the person with diabetes.
<table>
<thead>
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<th>Knowledge, understanding and experience</th>
<th>Freedom or bondage? The question of autonomy</th>
<th>Fighting fear in search for safety</th>
<th>Dealing with desires</th>
</tr>
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Table 5  The lived experience of adherence: main themes and subthemes

5.3.1 Knowledge, understanding and experience

The first theme analysed from the dialogues was knowledge, understanding and experience, which are necessary but not sufficient on their own to ensure adherence. Knowledge about the triangular interaction between diabetes, insulin and the body comes from various sources, as do the skills necessary for self-care, such as monitoring blood-glucose and injecting insulin.

Concrete knowledge is tried out in real life and experience teaches, by trial and error, what fits and what does not. Learning how the body reacts to different situations through body-listening becomes the art of the diabetic. Through combining the basic knowledge with real experience, understanding is gained. This process is dynamic and demanding, due to changes in diabetes care, personal development of the diabetic and changes in the disease and bodily responses. Time helps, but in spite of efforts to
adhere to the treatment regimen, sudden occurrences of hypo- and/or hyperglycaemia are common. Sometimes this all becomes overwhelming and, instead of adhering to the straight and narrow highway of ideal control of blood-sugar, a holiday may be taken for a while, in the countryside, on the winding back road of non-adherence.

5.3.1.1 Learning about diabetes and insulin and their effects on the body

In most instances information has been received soon after diagnosis of the disease from healthcare professionals, and is augmented from other sources such as websites, the Diabetic Association, and other people with diabetes.

Donna was diagnosed 15 years ago in her teens, and is struggling with her eating habits: ‘I could from very early on teach everybody how one should live with diabetes but very few knew how I behaved myself’(p.2). Frances has been highly adherent since childhood, but still has problems with hypoglycaemic episodes. She describes how she felt when she was introduced to fast-acting insulin: ‘I had tremendous difficulties eating immediately after injecting, instead of waiting first. It’s habit, but I also feel better if I wait before I eat’(p.21). And she tells me how difficult it is to adjust to new advice regarding her repeated hypoglycaemic episodes: ‘the dietician told me to choose breakfast based on my blood-sugar, but I don’t do it. I don’t know why, perhaps it’s just laziness’(p.12).

Elizabeth, diagnosed five years ago, is currently dealing with the knowledge aspects of adherence, along with everything else. She recently attended a course about living with diabetes: ‘if I hadn’t attended the course I would just have injected the insulin, eaten this food [without any carbohydrates] and then become hypoglycaemic’(p.3). She further describes how her knowledge is increasing:
‘initially I didn’t know at all what to eat, I injected up to 45 units, but it didn’t work because the blood-sugar was so high and I was eating incorrectly at the same time. I now know what to eat, but it would be good to learn more’ (p.36).

5.3.1.2 Listening to the body – ‘the guiding light’

After having learned the basics of diabetes care, my co-researchers described how they started juggling the information and recommendations given by healthcare professionals, to find a way to fit them into their daily life. To control their blood-sugar they use body-listening, with constant awareness throughout life. They become experts on themselves as they learn how different situations, food, activity, changes in the body or emotional status affect their blood-sugar. This complex, dynamic process takes much time and a lot of trial and error in order to learn what is right for oneself. Or as Donna says: ‘this constant observation has to be ongoing, all the time. Not ignoring the body when it is trying to tell me something’ (p.57).

Nonetheless this may not be sufficient, because the disease and the body can change and behave unpredictably like Liam experiences:

‘I’ve been learning to listen to my body, but the disease changes, my need for insulin has decreased and my feeling for glucose levels is impaired, so it’s difficult to find the correct dosage. Changes in blood-sugar are still surprising me’ (p. 26).

This awareness of the body is important, because it gives clues to the glucose status, as well as when and how to react to it. If it is impaired it may cause adherence difficulties. High blood-sugar can be hidden for a long time without any signs, and hypoglycaemic episodes occur without notice, ‘like a sparkle’ (Liam, p.3). Such ‘loss of hearing’ is also Brian’s experience, who has adhered meticulously for decades:
‘listening to the body, that is one’s guiding light. It was a huge loss when I stopped feeling hypoglycaemia coming, now I don’t feel anything, the thread is just cut and I am knocked out’ (p.3).

The optimal level of blood-sugar, as defined and recommended by the doctor, may be different from where the person feels safe and comfortable. Finding the most comfortable level is important for physical as well as psychological wellbeing, and was described by many co-researchers. Adherent people had a slightly different story to tell from the others: ‘when my levels are higher I feel comfortable, but I don’t want to be high because I know how it affects my vascular system (Frances, p.28). Those who had experienced longer periods of non-adherence did not feel comfortable or safe at their recommended level, and consciously raised it: ‘my long-term blood-sugar has been between 8 and 9, it’s not that I want it there but I feel better. If I stay under 7 I am constantly dropping’ (Kirstie, p.22).

The physical and psychological symptoms of hypo- and/or hyperglycaemia could materially affect adherence, because high blood-sugar can cause considerable discomfort: ‘part of wanting to adhere to the rules is because of the physical discomfort which follows high sugar, I become thirsty and itchy, and I smell’ (Hugh, who has remained adherent for decades, p.23).

With time, further knowledge is acquired about the body. The symptoms of high and low blood-sugar can be very similar and can be misinterpreted, as Donna has experienced:

‘my symptoms are twofold; I get symptoms when my levels are falling and very similar ones, with a subtle difference when I am 11-12. I used to wake up during the night, thinking my sugar was dropping and just grab something
to eat, but then I learned to check first, because sometimes I was high. There is just this very small difference. It’s similar if I am stressed out, it feels like my sugar’s dropping, but when I check, it isn’t so’ (p.34).

During long-standing non-adherence it is possible to ignore such signs. Elizabeth, who was diagnosed during pregnancy and refused to believe she was stuck with the disease forever, tried to ‘quit’: ‘when I decided there was nothing wrong with me I did not feel anything. I was just fine. But now I’ve started to feel my highs and lows again’ (p.4). With time the body will demand attention, however, and it becomes impossible to ignore it:

‘I can’t not look after myself because my body lets me know, with trembling and pain in the muscles and blurred vision. I never experienced this before. I suppose I’ve started listening to my body better’ (Kirstie, p.18).

This dialogue with the body also involves searching for causes which usually can be found. Occasionally however, the ever-increasing ability for detective work is not sufficient and: ‘I just don’t get what happened’ (Joan, p.17).

5.3.1.3 Learning self-monitoring of blood-glucose and insulin-injection

An important part of adherence is to check and record blood-glucose levels regularly, then decide the insulin dose and inject it correctly. The insulin injections were no hindrance for my co-researchers. A totally different story was told about self-monitoring of blood glucose, although modern technology, with inbuilt memory in the glucometer and quicker measurements, has superseded this hindrance for many and made life easier. Alan brings an interesting metaphor to this discussion:

‘checking my blood-sugar is like getting a warm pad when my shoulders ache, if I feel funny I will check it. I know I should do so more frequently,
and since I got my new glucometer I do because it is so simple.

Consequently, I have better control over my diabetes’ (p.16).

But Liam has problems with this part of adherence: ‘it just doesn’t fit into my daily life, it’s boring and it’s a nuisance to carry the stuff around. When you talk about it it’s not a problem, but in real life it just doesn’t happen’ (p.7).

Kirstie was negligent about her diabetes for decades, resulting in severe complications. Today she adheres strictly to her treatment regimen, aided by the technological progress in diabetic care:

‘I have never managed to keep records. I can’t stand stuff like that, there’s no way that I can keep some sort of diary in my bag. Today I just hand the glucometer over to my doctor... the glucometer was a revolution and made everything easier’ (p.11,16).

5.3.1.4 Learning to be organised and proactive in social context

Being adherent also means gaining the proficiency and courage to adjust the treatment regimen to different situations. When important or unusual situations arise, flexibility is necessary. It is important to be proactive and make arrangements, for safety’s sake. As Brian noted: ‘adherence is a lot about taking precautions, and pre-arrangements. Be like this or that before some events, like hiking or a funeral, something which is physically or emotionally stressful’ (p.59).

Keeping the disease under control becomes a challenging task, and applies to preventing both hyper- and hypoglycaemia. Alan has a stressful event coming up at work:

‘in order to be fit for this event, with my blood-sugar under control, I will check it more frequently for the next few days and see if I need more insulin
... when I am under emotional stress the diabetes goes wild, exactly when I need to think straight and be in control’ (p.40-43).

Liam’s main problems are frequent hypoglycaemic episodes: ‘I try to be proactive by increasing my glucose levels before entering stressful situations, like important meetings at work. Then I tend to become too high. It’s a constant balancing act’ (p.10).

Being proactive is also important in leisure. Liam, Frances and Gail all described how they have problems with hypoglycaemia after working out at the gym. And being away from home, during the day or while travelling requires great resourcefulness: ‘I have to pack food with me because I can’t rely on finding appropriate food wherever... I need a very strict framework to keep to my plans. Sometimes it works, sometimes not’ (Donna, p.29).

Adherence can interfere with the norms of politeness and unobtrusiveness, as Liam described:

‘situations that disturb my routine arise, like when I visit friends in their cottage. I can’t just rush to their fridge and eat whenever and whatever I like and the mealtime might be later than I am used to, perhaps it’s just me being modest but...’ (p.22).

Simple forgetfulness may ruin the day, as Joan has experienced:

‘I’m at full speed, out and about, feeling fine and then I get this kick in the ass, ah, I forgot to eat, and discover it by becoming hypoglycaemic, tired and all and then my energy fades, the energy necessary to keep on going and sticking to my plans’ (p.17).
Life with diabetes is a unique experience and felt by many as a very lonely one. Some of my co-researchers had been asked to share their experiences with others with diabetes, often young, non-adherent people with the intent of warning them. Others had found it helpful to meet more experienced people with diabetes. This sharing of experiences could affect adherence and was regarded important, because ‘people who haven’t got diabetes have no idea what it’s like’ (Kirstie, p.36).

5.3.2 Freedom or bondage? The question of autonomy

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

5.3.2.1 Independence and being responsible for oneself – the meaning of diabetes

Those who had considerable experience of non-adherence felt that some elements of the treatment regimen threatened their need for independence. The adherent persons had less difficulties fitting the regimen into their life, while the others put tremendous effort into finding a way to build it into daily life, give it priority and believe in its importance. This was experienced as a struggle between a sense of freedom or bondage. Finding a way to reconcile diabetes self-care with oneself, without jeopardizing independence, is the optimal goal.
Alan and Donna have a strong need for independence which affects their adherence: ‘being independent, perhaps it’s a question of looking after one’s health without letting the disease become the centre of what my life is all about’ (Alan, p.31). Donna reflects:

‘if my mother had been allowed to control my diabetes, it would have been perfect control, but what about my own psychological life? I would have been a dead character, because I just have to learn things myself, I have to make my own mistakes’ (p.64).

This need for independence can be so strong that control of the disease is perceived a private matter, no matter what. Joan has frequently been admitted to hospital because she has not been managing her hypoglycaemic episodes:

‘this control is my private matter, but it’s a problem how I think I can deal with it, and don’t seek help until very late. I should be able to manage and I know all about it, but then I don’t and end up in hospital, which is very uncomfortable, just like surrendering in a battle’ (p.28).

Those who had been non-adherent for a considerable time in their life looked back and reflected on how they had either changed or were trying to, in order to take responsibility for their life. Nobody else is going to do it, controlling their diabetes is ‘a battle I’m going to win’ (Elizabeth, p.23). And Donna says:

‘I started to work on myself and control how much I eat, but first and foremost it’s my head that needs help, then everything else becomes OK. This is just something I have to learn, to become responsible for my own life’ (p.9).
Sometimes irreversible complications of diabetes have been the turning point: ‘undergoing amputation, and seeing others in the same situation, that pushed me to stick to the rules, I was just glad it wasn’t worse, and stopped being so careless, I started to think it through’ (Ian, p.6).

Looking back, and reflecting on what taking responsibility means, was described by Alan:

‘my complications are my own fault, because I didn’t respect diabetes enough. I chose to take the risk of cheating on the strict behaviour which was expected of me. Living in such a strict and narrow pathway was just so... just such a constraint, that for me it wasn't an option. I wouldn’t have wanted to miss this part of my life, if it had to cost those complications then so be it. I was fully aware that my lifestyle might shorten my life, but I wanted to live fast and just live, even though it was in conflict with the disease. But only the best control is good enough, then you have become responsible for your own health’ (p.8-9).

Kirstie ignored her diabetes for a very long time, she reflects:

‘I never thought about it, never checked. Before, nothing changed even though I started to get serious complications... I have never become depressed or regretted what I did, it happened and I just have to deal with it. Today my blood-sugar is very important, my daily habits are all about keeping it under control... I have to live with diabetes today as one should, even though it’s a bit late for me’(p.4,11,36).

Joan describes how becoming a mother changed her sense of responsibility: ‘I participate more now in my own treatment and I have to look after myself better, to be able to look after my children. Thinking first about the children and then myself, that doesn’t suit diabetes at all’(p.18).
They set their own rules in their non-adherent periods, some kind of negotiation with themselves, and stuck to those no matter what: ‘I set my own limits when I drank alcohol, never to become helpless’ (Joan, p.4), ‘I ignored my diabetes from early on, but I set some ground rules for myself, I chose Prince Polo instead of Snickers, things like this were easy, but other rules I chose not to know about or see’ (Donna, p.1) and Liam says:

‘I’ve chosen to take care of myself in this way, somewhere between being accurate and careless. I have tried to create my own balance that suits my life. I am rather easy-going about it, to prevent it disturbing me too much. I am not interested in living my life through the disease, my diabetes is of no special interest to me’ (p.17).

Respect for the disease is a fundamental factor in order to control it; there was a consensus about this. However, my co-researchers varied in how they situated diabetes in their life, what it means to them. For some it had been allowed to control everything; all actions and decisions in life were evaluated from the point of the disease. Some had found peace with it, others fought a constant battle, while some just chose to ignore it as much as they could, with concomitant lack of control. Alan summarised this ‘relationship’ quite interestingly:

‘living with diabetes is like living with somebody, some furtive companion you can’t get rid of. You can ignore it but it is still there, doing things on its own, even if you’re not aware of it until one day it has already done some damage. Living with someone requires understanding and dialogue, and this dialogue with diabetes has improved with all the knowledge, talking with it, controlling it and being aware of it. This relationship is like that between a dog and his master. If you can discipline it, keeping it balanced in order to let
it follow you, if you can lead and control scrupulously, without being scared, without letting it control you, then you feel better. Those who manage this have mastered the disease’ (p.36-39).

All the co-researchers acknowledged their own responsibility and recognised the importance of respecting the disease. Brian noted: ‘when one feels that this has to be done [adhering], to have some well-being then it is not so difficult. I understood very early that one has the power to make one’s own wellbeing’ (p.5). Donna refuses to be stigmatised as a patient with a disease, diabetes is for her:

‘not a disease, unless you make it a disease. It’s just a certain lifestyle which I didn’t choose, I was just put there and in order to manage it I need first and foremost some emotional help... If you go on and on forever about things that you can’t do because of your illness, it will ruin your life… I just have to learn to respect [diabetes] and take care of it, because it has saved me in many ways’ (p.10, 16, 34).

5.3.2.2 Self-determination and controlling oneself – the meaning of adherence

Self-determination is an important part of adherence, to control one’s behaviour and life without interference from others, to follow one’s own convictions regarding the treatment regimen and clarify the meaning of adherence: ‘autonomy is so important, because I live by the motto of diabetes not being a disease which needs to be controlled or treated by others. I must be in control myself, otherwise I can’t be independent’ (Alan, p.7).

The threat of diabetes complications does not necessarily encourage adherence to the treatment regimen. Wellbeing today can be enough encouragement. But there are good days and bad days, as Donna described the second time we met:
‘it’s just each day that encourages me to keep my plan, the phenomenon of feeling well today because my blood-sugar is under control. On my bad days, like just now...I can feel how bad this is, but I always have to make the same mistakes again and again, and fall into the bad place to feel how bad it is’ (p. 23, 60).

Convictions about self-control may be hidden in self-deception as Alan describes:

‘I pretend to be convinced that I can control the diabetes by treating it lightly and not being dependent on it, then I check my blood-sugar seldom and rarely go to see a doctor. Sometimes I consciously bury what I know, in order to enjoy more freedom. But freedom and bondage, there is just a short gap between those two, because I know that if I don’t look after myself my life can become just one big bondage. If my mind goes because of diabetic complications, then I have lost everything, quality of life, autonomy and independence’ (p. 34).

Adherence is about self-discipline and constant awareness, being in control. It is a prerequisite for wellbeing and being able to enjoy things in life. It takes determination and patience, every day, all the time. This ‘balancing act’ is easier said than done, though, even for the most adherent persons like Brian:

‘the reward of adherence is when the check-ups are OK, and few episodes of hypoglycaemia. But it’s easier said than done to follow this fine line, so little needs to go wrong for you to have too much or too little sugar’ (p. 42).

And Donna, who has used the 12-step programme to aid her adherence, says: ‘it is very hard, emotionally, to find this balance, and I am grateful to have my programme to help me’ (p. 63).
However, mastering the balancing act is not the only challenge. Simply dealing with bad days can ruin good intentions: days when life is not in order, for whatever reason, make adherence difficult. For Joan, bad periods are characterised by sheer carelessness: ‘I don’t test my blood-sugar and don’t care at all. I just eat and eat’ (p.6). And on her good days, none of this is a problem: ‘I decide that I don’t have to taste this and that, I just decide I don’t want it. I decide things like this’ (p.30).

Not being able to control blood-sugar causes shame and embarrassment. Many of the co-researchers commented on this, including Kirstie: ‘when everything’s out of control I go into hiding. Everybody’s supposed to think everything is fine. It’s just like an alcoholic who hides his drinking. My sugar’s always dropping, many times a week, and I don’t tell anybody’ (p.36).

5.3.2.3 Knowing oneself

Personality and personal characteristics affect adherence, and can either aid or hinder it. In order to understand oneself and make a realistic plan to improve glycaemic control, certain self-examination takes place. Thus the theme ‘knowing oneself’ was analysed, when co-researchers described themselves, along with their ability to adhere.

‘I’ve always been described as a quick-tempered person; I am extremely energetic, very independent and stubborn. And fussy with food… I was always getting advice about something that just didn’t fit with me like eating bread with cheese. I still don’t eat cheese, never have’ (Kirstie, p.13).

And Liam says:

‘I am very stubborn by nature and it is not easy for others to tell me what to do. I have to realise myself the consequences of my behaviour, and changing it would have to happen in an informed way and by my own decision’ (p.8).
Frances has not had problems with adhering to the regimen. However, her blood-sugar control is suboptimal:

‘I think my character just helped me adhere so well. I am a ‘by-the-clock’ person, very conservative and orderly, everything has to be in the same drawer… I can’t change my habits, for example eat more and inject more. I can’t enjoy the freedom that came with the new insulin types, but I don’t feel I’m missing anything’ (p.12,16-17).

5.3.2.4 The value of support

Support is mentioned by almost all the co-researchers as an important factor in adherence. It comes from different sources, family support frequently mentioned as most important. Furthermore, it may come from others with diabetes, self-help groups or the Diabetic Association. Faith was mentioned as helpful in the search for determination and self-discipline, as was the 12-step programme of Overeaters Anonymous. However, support from others can easily turn into its opposite and become interference and criticism, which makes people vulnerable, threatens their need for autonomy and may even drive them into even more covert behaviour. Although support was important, adherence was regarded as a very private matter.

Both Donna and Kirstie felt from early on that they needed ‘something,’ but it was difficult to conceptualise it: ‘I needed others who knew what I was talking about, but didn’t make any demands (Donna, p.41) and Kirstie says: ‘everybody wanted to help, but still I didn’t get what I needed. I don’t know what it was but certainly not all this scolding and screaming, it just made things worse’ (p.16). Many co-researchers felt that self-help groups might provide support, although few had experience of them.
5.3.3 Fighting fear in search for safety

The experience of adherence is coloured with fear or deep concern: of diabetic complications and suffering. More immediate is the fear of hypoglycaemia which impairs quality of daily life. And there is fear of one’s behaviour. When adherence is not manageable, the fear of reality may become overwhelming, resulting in denial and ‘lying to oneself’.

Fear must be managed because it interferes with quality of life: ‘fear is totally destructive for me; it has never encouraged me to change my behaviour. I can feel it and it scares me but it doesn’t make any difference’ (Donna, p.59). Alan has also given this some thought: ‘if you are going to live with diabetes for decades and are scared of it the whole time, that’s terrible. One has to defeat fear because it isn’t going to go away’ (p.37).

5.3.3.1 Fear of hypoglycaemia

Hypoglycaemia is common in strict adherence, or when the disease is badly controlled. When blood-glucose is kept within narrow limits, the risk of hypoglycaemia increases. Failure to avoid hypoglycaemia leaves the person scared and frustrated, and impairs quality of life to a great extent. This applies to different situations, both at home and away: ‘I never feel safe when I go to bed, I never know if I’ll wake up hypo or hyper’ said Frances (p.21). And Gail had similar experience: ‘becoming hypoglycaemic is worst of all, especially if you are somewhere where people don’t know you’ (p.31). This fear affects adherence, because blood-sugar may be kept higher than is desirable in order to prevent hypoglycaemia.
5.3.3.2 Fear of diabetes complications

All the co-researchers realised, if they had not already experienced it, how their non-adherent behaviour might increase their risk of diabetic complications. This knowledge scared them to a certain extent: ‘my main worry is that I could go blind’ (Donna, p.59), and Alan said: ‘I am just grateful for my mind being intact, that is what I fear most’ (p.35). This can affect future plans as well: ‘I don’t expect to live to be very old, so I don’t plan my retirement savings as I would if there was no diabetes’ (Liam, p.20).

Fear could encourage adherence: ‘I knew I could lose my health, and for a long time I didn’t really believe it, but I knew it was safer to eat correctly’ (Brian, p.9). Controversial experiences were also described: ‘I had some preliminary changes in my eyes; I was stressed and scared but not enough to do anything about it’ (Donna, p.59).

5.3.3.3 Fear of the truth

Most of the co-researchers acknowledge that they have, at some time, deceived themselves when reality hit them hard. During their non-adherent periods they would pretend that things were not so bad, that complications happened to others. Doctors or other healthcare professionals challenged this. Being told off hurts and ‘lying to oneself’ became ‘lying to the doctor’, in order to modify the truth a little, because it was hard to swallow. Some reacted by failing to bring in records of blood-sugar to the doctor, or bringing falsified ones: ‘I was altering and modifying all the time, it looked perfect on paper, but then the long-term blood-sugar was terrible, so I couldn’t fool anybody, of course’ (Elizabeth, 15). Both Hugh and Joan tried to make things right before their next appointment by exercising more or eating correctly to bring their sugar down, but did not always succeed:
‘I got a bad conscience, a long time would pass between appointments because I was trying to manage by myself. It wasn't working and then the fear would come, and I would go hiding. I just felt so much worse when I went to the clinic and got told off’ (Joan, p. 9).

Facing the truth can be tough:

‘the doctor was just telling me the truth, and I couldn’t stand him. But one has to accept the truth and do something about it, it’s either that or letting diabetes take over and win... and kill you earlier than otherwise. The choice is mine. But sometimes I just fall into this phase of not wanting to know that I have this disease. And just eat my sweets and my Coke and be like normal people’ (Elizabeth, p. 6).

5.3.4 Dealing with desires

Dealing with desires is part of the lived experience of adherence, described by all the co-researchers. Desires are part of life and quality of life: to do what we want, right now or in life in general. A constant dilemma is created when ‘good’ versus ‘bad’ desires are competing within oneself. The desire to do right competes with longings for normality, as well as for something ‘unhealthy’ which may disturb blood-sugar control.

5.3.4.1 Desire to do right

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

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

‘I try to do everything right but I don’t always succeed. I feel so much better when I stick to the rules and manage to stay under 8... I feel light and happy and am determined to do exactly the same again’ (Elizabeth, pp.4-6)

Wanting to do right and not managing it results in pangs of guilt and negotiations with oneself, trying to stick to the rules and reward oneself instead: ‘of course I would feel guilty, ‘oh my God, what have I done, eaten three sandwiches instead of one’...now I try to control what I eat and reward myself with good food’ (Donna, p.11).

The desire to do right also affects important decisions like becoming pregnant or dealing with unplanned pregnancy. Kirstie became pregnant while totally ignoring her diabetes: ‘everything changed because I started taking better care of myself, because it wasn't just me to think of. I was advised to have my pregnancy terminated, but I was stubborn and refused’(p.5). Joan also carried on with her unplanned pregnancy, in spite of a health professional’s comment that she would ‘kill her baby’ because of her poor control:

‘I feel guilty when I don’t take care of myself. But when I became pregnant things changed, I decided to shape up, and have never been more stable because then I was thinking about another person. Now I can’t just think
about myself because they need their Mum, that’s what encourages me the most to adhere’ (pp.7-9).

Conflict between desires was common: ‘throughout my life this desire to do right would sometimes disappear and get buried under my other desires, desires to do this and that which wasn’t right’ (Alan).

5.3.4.2 Desire to be normal

‘To be normal’ is an important element in people. The stigmatisation of diabetes threatens the need for normality, and affects the experience of adherence. It was important for my co-researchers to define themselves as healthy, no different from others, and to avoid attention: ‘nobody is supposed to see that anything is wrong with me’ (Kirstie, p. 34).

They would try to find a way to be like others and not let the treatment regimen stop them, neither in leisure nor daily life. They did this in diverse ways. There were examples of total negligence in care: ‘I’ve never let my illness stop me doing anything I want. I sometimes got into trouble, but nothing would stop me’ (Kirstie, p. 9). Others struggled with the dilemma of adhering strictly to their regimen while simultaneously participating in normal social activities like dining out or travelling.

Achieving balance is the ultimate goal, to reconcile the treatment regime with being normal. Gail has done so, and enjoys long-distance travel, hiking and a busy personal and professional life without compromising her adherence; being normal is very important for her:
‘my whole life it’s been like this, not wanting to be different, and I can’t get rid of it. I always leave the room, for example if I’m in a meeting, to grab a bite or check my blood-sugar’ (p.14).

Even if the decision has been made to not hide the disease, in order to aid adherence, the environment, at work for example, may not be receptive. Liam’s colleagues made complaints, and he started to manage his diabetes covertly: ‘I’m delaying my checks and injections at work, messing up my routine and not taking as much care, because I’m hiding the disease and its treatment’ (p.24).

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

Those who might be described as adherent had different experiences from the non-adherent. Their desires were not so insistent, so extreme, so difficult to handle. Food and sweets, alcohol, an irregular lifestyle or extreme activities were not major temptations for the adherent person: ‘food is not important to me at all, I just eat because I have to’ (Gail, p.19). Those who had been non-adherent were bombarded
with desires: ‘one is tempted with so many things and one gives in, indulgence is the word for it...’ (Alan).

If the desires are ‘good’ and represent something which increases quality of life, they are not seen as worth overcoming. Instead, the person negotiates a way to control blood-sugar while enjoying those ‘temptations’. Both Alan and Liam enjoy participating in sport, which makes their control very difficult: ‘I have to be very careful, because I tend to become severely hypoglycaemic afterwards. But I believe it improves my health otherwise, and would never think of quitting (Liam, p.20). Emotional stress requires care as well ‘but I wouldn't avoid it just because of the diabetes. Rather take precautions’ (Alan, p.41).

5.4 Main themes: relationship with healthcare professionals

5.4.1 Introduction

Part of the research aim was to explore with the co-researchers how non-adherence affects their relationship with healthcare professionals. As most of them have a history of decades with the disease, they had a long story to tell. It was coloured by the status of medical knowledge and availability of healthcare services at any given time. For many, physicians, dieticians or nurses with special knowledge of diabetes, as well as out-patient clinics, were non-existent until years or decades after their diagnosis.

About half the co-researchers attend an outpatient hospital clinic; the others go to their doctor’s private clinic. A few rarely (once or twice a year) visit their doctor.

They described how their encounters with healthcare professionals, mainly doctors but also dieticians and nurses, have at times been paradoxical in nature, depending on
individual professionals, their own level of adherence and time. In retrospect these encounters were perceived differently, but it was apparent that for many the relationship with healthcare professionals was a power-struggle. Healthcare professionals are part of the adherence experience and their communication approach set the tone for supporting or not supporting adherence.

Attendance for check-ups differed between those who can be described as adherent and non-adherent. The adherent persons go regularly (every three months) for screening for complications, and to have their long-term blood-sugar checked. The others attend less regularly. They may perceive it as waste of money and time, because there is nothing more to be learned and the glucometer gives a good indication of their control. Others find it reassuring to go and be told if things are in order, and they seek advice and help when needed. All of them want to be kept up to date with developments in diabetes care.

5.4.2 Communication approaches
My co-researchers described their encounters with healthcare professionals (usually doctors but rarely nurses) when they had not been adhering properly to the treatment regimen. They acknowledged, in retrospect, that healthcare professionals were probably ‘doing their best’, telling them the truth and worrying about their non-adherence. However, these concerns did not sufficiently counterbalance the effects of disabling communication approaches. Even if enabling approaches were not sufficient to improve adherence, they were certainly encouraging, and met their need for respect and care.
Table 6 shows the analytical framework for this second part of the study, the communication approaches that doctors and other healthcare professionals can and do use in their encounters with non-adherent diabetics:

<table>
<thead>
<tr>
<th>Enabling</th>
<th>Disabling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interested</td>
<td>Not interested</td>
</tr>
<tr>
<td>Provide with information</td>
<td>Withhold information</td>
</tr>
<tr>
<td>Respect autonomy</td>
<td>Disrespect autonomy</td>
</tr>
<tr>
<td>Personal inquiry</td>
<td>Routine and impersonal</td>
</tr>
<tr>
<td>Approach as equals</td>
<td>Patronising approach</td>
</tr>
<tr>
<td>Understanding and supporting</td>
<td>Reprimanding and telling off</td>
</tr>
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**Table 6 Enabling and disabling communication approaches**

**5.4.2.1 Interested vs. indifferent**

Healthcare professionals, who are interested in diabetes care, encourage and support adherence. They make the effort to put the message across about the disease’s progress, its effects on the body and the importance of adherence: ‘my best doctor was interested, he’d explain what was happening and draw pictures to explain. Today, my doctor presumes I know it all, I suppose I do, we don’t talk much about my diabetes’ (Frances, p. 44).

**5.4.2.2 Provide with information vs. withhold information**

Living with diabetes for decades leaves little to be learned from healthcare professionals. However, there are expectations of being kept up-to-date about developments in diabetes care, which can influence control tremendously. Thus better glucometers and insulin can make life easier and improve adherence. This is not, however, what always happens; sometimes doctors withhold information:
‘I first heard about long-acting insulin from my uncle and thought it might help me. So I went to the doctor and asked about it, and he said ‘oh, do you think that would suit you?’ and it certainly did, it changed things tremendously for me’ (Donna, p.16,21).

This responsibility is mutual, however. The diabetic person also has obligations, to make and keep appointments and talk with healthcare professionals:

‘as patients we have to share information with the healthcare professionals and respect this part of communication. We know how we feel and we have to tell the truth, not hiding and not exaggerating our condition’ (Alan, p.23).

5.4.2.3 Respect vs. disrespect of autonomy

As described earlier, autonomy is very important, but may be threatened in encounters with healthcare professionals. It can take years to gain the confidence to protect one’s autonomy and assume control: ‘my doctor wants to set very narrow limits, but he knows that if he demands and makes conditions, I won’t come for a long time. He has realised that I’m the one in control’ (Alan, p.53).

Donna felt her autonomy was threatened when she came to the clinic with low blood-sugar and was compelled to stay until her sugar was ‘high enough’ (according to the staff). She said:

‘I was so angry; they took my autonomy away, even though it was only for 15 minutes. This was no big deal, my sugar drops all the time outside the hospital, I eat and then I’m okay. Things like that just make you leave and never come back’(p.53).

5.4.2.4 Personal vs. routine and impersonal inquiries

My co-researchers had diverse experiences of seeking help with their control. Personal attention, with the focus on them as individuals and their life with diabetes
influenced them more than listening to a routine lecture about what to do. Being asked about personal matters came as a nice surprise: ‘my doctor asked me about my marriage and our sex life. This was completely new to me, to connect the disease with my personal life’ (Hugh, p.32).

Routine and impersonal communications are ineffective, as Liam experienced when he made an appointment at the out-patient clinic in search for help with his control:

‘the dietician just recited some figures about protein and all this stuff. I didn’t gain much from that. But I suppose she was doing her best. And the doctor, he held a 15-minute monologue of blame. Being reprimanded like that, just like a dog, what for? I was on my first visit, and he was just like a cassette in a record player, churning out all the lore in this derogatory way, just as if I was a fool. I couldn’t ask him about anything I wanted to, and just left and never went back’ (p.2,20).

5.4.2.5 Approaching as equals vs. patronising approach

‘Nobody has the right to tell you what you should do, and what not. It’s important for doctors to consider how they say things. We need different help and advice, and if I hadn’t been so scared of my doctor, and stubborn myself, things might have been different’ (Kirstie, p.48).

The relationship between my co-researchers and healthcare professionals is a function of equality, of being approached as equals or in a patronising way. In the latter cases it was acknowledged that probably the doctor meant well, but this approach simply does not work: ‘I used to fight with my doctor all the time, he would be angry with me for not taking better care of myself, and I ended up just screaming back at him’ with the result of non-attendance: ‘I felt I was talked down to, got fed up, and stopped going to him’ (Elizabeth, p.2).
The opposite was sometimes the case:

‘I have always liked my doctor; he has never spoken down to me. He makes me realise how serious things are, but in a human way, which I find most important. I’ve always listened to him, he just knows how to approach people like me’ (Kirstie, p.29).

5.4.2.6 Understanding and supportive vs. reprimanding and threatening

Some co-researchers could compare different approaches in their encounters with different professionals. Joan had experienced constant debilitating conflicts when she attended the clinic, but now she feels able and willing to change, to take control, because she has met a completely different attitude:

‘with my doctor now, we just click, she was so positive and glad to see me coming in and getting help, and then everything started to change too. Now I go in there happily, with my records, and she talks with me, asks me: ‘what do you think about this?’ I’m involved now, more a participant in the treatment. Before I was just sent out with some figures, ‘this is what you should do’. And I’m invited to see the dietician or to attend a course – before I was just sent’ (pp. 11,15-16)

5.5 Summary

The study revealed four main themes that describe the lived experience of adherence and non-adherence. This is a dynamic experience, affected by differences in the intensity and interaction of the themes, as well as changes in time and space. Healthcare professionals can play an important, supportive role in adherence, but if they do not, the person will limit the contact as much as possible. Figure 6 (page 76) displays those main findings graphically.
**Figure 6** The lived experience of adherence and/or non-adherence with affecting social factors: Those can be potentially supporting (broken red arrows) or either supporting (red) or non-supporting (blue) depending on individual circumstances.
Chapter 6
Discussion, implications, strengths and limitations, and recommendations for further research

6.1 Introduction
This study explored the lived experience of adhering to a prescribed treatment regimen for diabetes, with the purpose of enhancing understanding of the concept and make the patient’s perspective heard in this context.

Before I start to discuss the findings, I want to emphasise that they are bound by constraints of time, place and circumstances, and can only be seen as illuminations of my co-researchers’ experiences, not to be generalised to a wider population.

Four main themes describe the lived experience of adherence, with subsequent sub-themes. The themes and sub-themes interact with each other and are sometimes in conflict. The second research question addressed the patient-provider relationship in case of non-adherence. Here, enabling and disabling communication approaches were found to be influential.

6.2 Discussion
Some of the study’s findings are consistent with other studies that have addressed the issue of adherence, although no phenomenological studies were found for comparison. The first theme analysed was ‘knowledge, understanding and experience’. This may be the best-recognised aspect of life with chronic illness, and is a prerequisite for successful self-management. Within the healthcare services non-adherence is frequently explained as a matter of knowledge deficit (Russell et al.,
Within the literature that criticises non-compliance research and its focus on the patient as the problem, compliance has been conceptualised as primarily a question of professional power (Playle and Keeley, 1998), and a phenomenon socially constructed by healthcare providers (Fineman, 1991). In this study, the most interesting findings reveal the importance of autonomy and how deeply it affects the patient-provider relationship. No similar findings were found in other studies with the possible exception of Conrad (1985, 1987). He has termed the non-compliant patient ‘in search of autonomy’ and presented the idea of non-compliance and self-regulation being two conceptual models, two sides (patient’s and provider’s perspectives) of the same coin.

6.2.1 Autonomy

Autonomy involves independence, self-determination and self-care (Redman, 2005). These concepts appeared frequently in my co-researchers’ narratives, although their importance varied between those who had problems and no problems with adherence. The treatment regimen and/or healthcare professionals can and do threaten patient’s autonomy. Insulin treatment means dependency in itself, and strict adherence to other aspects of the regimen means further dependency for many, disrupting the flow of their daily life. They started negotiating the regimen and disease with daily life, in a process that Hernandez (1996) calls ‘integration’.

6.2.1.1 Independence and the meaning of diabetes

Those who had no problems with adherence had always prioritised diabetes: it was in the foreground of their lives. Some managed to care successfully for themselves without
jeopardizing their quality of life, while others felt that their life had always revolved primarily around diabetes. Still others coped with the restrictions the regimen imposed on them by putting it in the background of their lives, in an attempt to feel free, healthy and normal. Those findings are in accord with the model of ‘Shifting Perspectives’ (Paterson, 2001b) which was presented in Chapter 2.

People with diabetes are subjected to many paradoxes and contradictory messages. They experience dependency and loss of control over their life when adhering strictly to the regimen, but being non-adherent to the extent of negligence can mean losing control over the body, with subsequent diabetes complications and dependency. Furthermore, they are given two contradictory messages simultaneously: ‘be in charge and responsible for your life’ and ‘do what we (healthcare professionals) tell you to do’.

The meaning of diabetes relates to the need for independence, according to the findings. Different meanings may be the foundation of differences in dealing with the disease in one’s life, and attaining what Hernandez (1996) and Paterson and Thorne (2000) have termed the phases of ‘science of one’ and ‘active control’ respectively: i.e. the disease has been integrated into their lives, they have assumed control and decided to take care of themselves.

In this study, many of the co-researchers personified diabetes as she (diabetes being a feminine noun in Icelandic), their descriptions may be summarised as following:

**She** is there, in their lives, an uninvited companion, quiet and invisible initially but constantly pottering around, and dangerous if ignored for long. She must be taken care of and respected, but how much she is allowed to affect your life, threaten your independence and dominate your actions is up to yourself. You can ignore and neglect her, or give her all your attention and priority, you can fight
her and hate her, but also appreciate the restrictions she puts on your ‘bad’
behaviour. Respecting her means to prioritise her, because attending to oneself
first and then diabetes does not suit her: she will take her revenge.

Those who have reached this stage of understanding have the main goal of taking good
care of her, keeping her as a disciplined and obedient companion in a ‘backroom’ of the
mind. The challenge is to find ‘balance’, and balance is a recurrent theme in my findings
as well as in the literature on the diabetes experiences, in fact it is stated to be the
‘determinant metaphor’ in that experience (Paterson, Thorne and Dewis, 1998). Such
personifications of diabetes were, however, rarely found, with the exception of Hartrick’s
(1998) study where diabetes was described as having authority over the person, and in
Koch et al., (2000) where living with diabetes was described as ‘carrying a passenger.’

6.2.1.2 Responsibility and the privacy of self-management

‘Whose responsibility is diabetes care?’ has been asked ever since diabetes became a
chronic illness (Feudtner, 2003). Non-adherence is frequently characterised as irrational
and irresponsible behaviour (Russell et al., 2003; Wens, et. al, 2005), although many
studies contradict that view (Coates and Boore, 1998). My findings portray a complex
picture of individuals who have acknowledged responsibility for the disease management
as being theirs, as well as the diabetes complications they have or may acquire. They fully
intend to do their best to control the disease, even though they do not always succeed.

Another interesting finding was how many struggled with management of the disease
more-or-less on their own. I assumed that support from healthcare professionals could be
helpful, but found out that this management is a very private matter and there is a
tendency to not seek help until very late. Privacy is an attempt to avoid attention, but also
a manifestation of the need for independence, and a strategy to cope with the shame, guilt
and frustration many felt when they were not managing well enough. Diabetes then became a problem and an illness, similar to what Corbin (2003) describes; that the fear of losing control over one’s body, of not being able to trust it anymore and no longer understanding its language, constructs the experience of illness. Hypoglycaemia has been described in studies as an extremely private experience which is rarely discussed with others (Ritholz and Jacobsen, 1998) and causes negative impact in both interpersonal relationships and views of oneself (Rajaram, 1997). Similar descriptions were found in my study. Some of those who had difficulties with hypoglycaemia consciously decide to raise their blood-sugar levels in an attempt to prevent such episodes, and many do not ask for help to learn to prevent them. By the same token, hyperglycaemia was indicative of their failure to eat correctly.

This lack of confidence in healthcare professionals’ ability to help gives rise to concern. Many felt, however, that meeting others with diabetes might be helpful and studies have demonstrated the benefits of organised peer-support (Hernandez et al., 1999; MacPherson et al., 2004).

### 6.2.1.3 Self-determination and the meaning of adherence

Self-determination means to be free to make one’s own decisions without interference from others, and to have those choices respected. The treatment regimen had initially been perceived by many as an oppression (because it was never negotiated or designed by and for that individual?), causing them to rebel against it.

With time they adapted the regimen, and learned to value it as a way to take care of diabetes and thus oneself. It became ‘a lifestyle’ or an ‘arrangement’ in life in order to achieve wellbeing, sometimes easy to follow, a habit, similar to many others. At other times it presents constraints to freedom, because situations and longings arise which
require new adjustments, even temporary neglect of the regimen. Some are important and are given priority (many social situations for example), others are weaknesses that must be resisted, such as ‘carelessness’, ‘lack of self-discipline’ or ‘being stupid’. A picture of life, characterised by everlasting shifts and lack of stability, even for the most adherent was portrayed. Life with diabetes is sometimes perceived as a burden, illness and loss, but at other times normal, healthy and encouraging. These perceptions vary from one individual to another, but the complexity of feelings exists within each person. It is interesting to compare this with the metastudy of client roles in qualitative research on chronic illness experiences conducted by Thorne and Paterson (1998). In research reports published over a 20-year period, they detected a shift in the conceptualisation of individuals with chronic illness, from a focus on loss and burden towards images of more optimistic descriptions. My findings suggest that within each person all those perspectives exist, changing with time and situations.

It was challenging to approach my co-researchers with the concept of adherence, what is the meaning of ‘adherence’ for them? Interestingly, Icelandic has no word for adherence, with the exception of a noun that means literally ‘keeping to treatment’. It was coined and is only used by healthcare professionals, can not be found in dictionaries, and my co-researchers did not recognise it. This fact was crucial to their perceptions. For them, the regimen presented an expected behaviour, prescribed by healthcare professionals, in order to control their blood-glucose. For them, ‘balance’ and ‘control’ did not have the same meaning as for their providers. They frequently chose to modify the regimen or be selectively compliant, similar to what Thorne (1990) has described; attending carefully to some aspects of self-management while ignoring others, sometimes occasionally, at other times continuously, and modifying the regimen according to their needs.
6.2.1.4 Knowing oneself

The ‘uniqueness’ of each person was a concept that gradually arose in the dialogues. Differences in people’s values and preferences, characters and personalities, vices and virtues, as well as social circumstances, determine to some extent their experience of adherence. Controversially, the treatment regimen seems to be universally prescribed for all. It is rarely negotiated or designed by the person with diabetes, although there is a trend towards this approach in current diabetes care (Eggertsdóttir, 2005). My co-researchers who had difficulties with adherence found it intolerable to be told how to behave by healthcare professionals; they knew it perfectly well already. They needed different help from what was on offer. Although they had difficulties conceptualising it, my interpretation is that they were calling for being recognised and treated as the person they are, and not only the case or the patient, similar to what Liaschenko (1997) has conceptualised as ‘knowing the patient’.

6.2.2 Fear

The fear diabetes imposes on one’s life is another construct of adherence and different fears were described by my co-researchers. Healthcare professionals confront them with a truth which hurts, and a common reaction is lying to oneself and sometimes lying or deceiving the doctor. Self-deception or ‘reality avoidance’ are concepts frequently used to describe non-adherent people in a judgmental way. This human way of reacting to a threat is seen when a person persuades himself to believe what he knows is not so, believing two contradictory things at the same time. It thus involves an inner conflict, or an existence of ‘contradiction’ which Plato called ‘true lie’, or the lie ‘in the soul’ (Demos, 1960). Reality avoidance is a known construct in life with diabetes (Gillibrand and Flynn, 2001), and Funnel et al. (1990) suggest that accepting the reality posed by diabetes and the possible long-term complications provides a sense of unrelenting vulnerability, a state that is resisted or avoided as much as possible.
The threat of vulnerability has been described by Weiss and Hutchinson (2000). Participants in their study (with diabetes and hypertension) described how they were repeatedly bombarded with warnings, both external (from others) and internal (from themselves). The internal warnings were found to be far more influential in affecting adherence. Threat is commonly used by healthcare professionals to bring about adherence (Wens et. al, 2005), and many of my co-researchers had experienced this. For those with difficulties adhering, external warnings had been ineffective. What they needed was ‘something for my head’; the internal warning (their own fear) was there, but was not sufficient to help them change their behaviour, even when they really wanted to. For the more adherent, fear supported adherence.

6.2.3 Desires

Desires influence the experience of adherence; they compete within the person, trying out his or her self-discipline, strength and/or lack of willpower. Humans are capable of wanting to be different in their preferences and purposes from what they are (Frankfurt, 1971). They are able to form ‘second-order desires’, that is, wanting to have certain desires or wanting certain desires to be their will (first-order desires are simple longings for something). This will is the ‘essence of being a person’ noted Frankfurt (1971), and perhaps it is never as immediate as in adherence, where first- and second-order desires constantly conflict within the person.

The desire to be normal is well known in the chronic-illness literature (Gillibrand and Flynn, 2001). Advances in diabetes management have given many people increased freedom, and made it possible for them to live a more normal life. Although many of my co-researchers praised this change, others had not managed, or were not interested in taking advantage of that freedom, as it involves a more complex treatment regimen. Such negative aspects of advances in medicine are rarely addressed by
healthcare professionals, but in diabetes care they have existed since the introduction of insulin (Feudtner, 2003).

**6.2.4 Relationship with healthcare professionals**

The second part of the study explored what happens in the patient-provider relationship when patients are not managing well enough, according to healthcare professionals.

Non-compliance was invented by healthcare professionals, defined by them as a deviant behaviour, a problem to be solved. It is based on their assumptions about health, management of diseases, and their role and that of the patient in healthcare relationships. These assumptions are rooted in the biomedical model and reflect a perspective which honours ‘healthism’, prioritises disease over life, and simultaneously ignores the ‘lifeworld’ of patients. This attitude is based on the notion of beneficence, although the possibility remains that healthcare professionals’ intent (conscious or unconscious) may, at times, be ‘self-serving’ instead of ‘other-serving’ (Mitchell, 2002).

**6.2.4.1 Ethics and adherence**

Respect for human beings is the most important idea in ethics, and the one most difficult to adhere to (Árnason, 2003). Healthcare professionals have a certain power over patients due to their expert knowledge and status within society. They also have ethical principles to guide their practice, those of autonomy, beneficence and justice. The former two may create an ethical dilemma which, in the issue of non-adherence, is the crucial problem.

Healthcare professionals have ethical duties that may be negative (withhold action) or positive (action). When in conflict, the general rule is to respect the negative, i.e. we should not do something that may benefit a person if it compromises her autonomy. The patient has two similar rights, positive (to refuse treatment) and negative (to have
something done for him). Negative duties of professionals and positive rights of patients address the issue of autonomy, while positive duties and negative rights relate to the issue of beneficence (Árnason, 2003).

The paternalistic methods of using coercion or threat to bring about adherence are well known, and are justified by the notion of the patient’s interests. To evaluate them, it is useful to consider the three perspectives: biomedical (focus on disease), ethical (focus on ethical principles) and personal (the individual’s values, judgment and wishes). What is important here is to make sure that the patient can make decisions that are based on correct information, and that no misunderstanding has occurred (Árnason, 2003).

The challenge for healthcare professionals lies in finding a balance between the notion of beneficence, avoiding paternalism; and extreme respect for autonomy which Hess (1996) has termed ‘isolated autonomy’. It involves indifference to patients’ decisions and detachment, a certain ‘consumerism’ where information is given without any recommendations. The proposed solution to this dilemma has been termed ‘engagement’ (Hess, 1996) or ‘authentic conversation/dialogue’ (Árnason, 2003), and involves a different kind of communication, based on mutual trust and responsibility, respect for each other’s expertise and acknowledgement of equality between two human beings. Respect for autonomy requires healthcare professionals to actively assist their patients in making decisions about treatment, and then to accept those decisions (Olsen, 2000).

6.2.4.2 The reality in the relationship

The patient-provider relationship has received much attention lately, and when ideal it is recognised as the key solution to many dilemmas within healthcare. Whether the intention is to promote more ethical, humanistic or safer care, or improved adherence, the focus is on the communication between patients and providers.
My findings revealed how certain communication approaches enable adherence, while others have a disabling effect. Different people, at different times, need different approaches; this individualised approach is crucial if healthcare professionals want to make a difference to their patients. Similar findings have been published by Hornsten et al. (2005) from their qualitative study on patient satisfaction with diabetes care. Here again, the notion of ‘knowing the patient’ (Liaschenko, 1997) is of paramount importance and provides the context for ethical treatment (Olsen, 1997). Individualised care has been conceptualised as occurring when the nurse knows the patient as a unique individual; and tailors nursing care to patient’s experiences, behaviours, feelings and perceptions (Radwin and Alster, 2002). Very few of my co-researchers described such a relationship. In fact, their encounters seemed to be more similar to the ‘consumerism’ described above, with physiological check-ups, information on new treatment options on the market and re-supply of medication and monitoring devices. They do, however, rely on their doctor for assistance when sick and when serious difficulties with the management of the disease arise.

The discourse on compliance is changing, as is evident in the literature. It insists on moving the focus from the patient to other dimensions of adherence, such as the patient-provider relationship and healthcare professionals’ attitudes and practice. It furthermore insists on re-evaluation of how services are organised, and the philosophy and values those services are based on. There is a call for reconceptualisation of the roles of patients and professionals (Playle and Keeley, 1998) and for acknowledging society’s responsibility, taking into account factors like health literacy (Erlen, 2004), access to services, poverty and other health disparities.

The attitudes of providers need consideration. Attitudes towards practice are moulded within their curriculum and further supported with role-models at the area of practice.
Non-adherent patients are frequently defined as ‘difficult’, and studies show that nurses avoid or distance themselves from such patients (Shattell, 2004). My ‘non-adherent’ co-researchers described experiences of such negative attitudes, both within hospitals and in the diabetes out-patient clinic. This made them withdraw and/or stop making and keeping appointments. The consequences of such an attitude may be discrimination in services, which is unethical.

My co-researchers’ lack of enthusiasm about emotional, psychosocial support at the clinic is a cause of concern. ‘It’s my head that needs help’ was their conclusion, but such help was rarely available at the clinic. This suggests that the present model of care does not offer psychological support to any extent. A similar ‘deficiency in the system’ is described by Zoffmann and Kirkevold (2005) in their study on interactions between healthcare providers and diabetes patients in poor control. Psychosocial problems, including depression, have been found to be very common among diabetic patients worldwide, for example in a recently published report of cross-national diabetes attitudes, wishes and needs (DAWN study) (Peyrot et al., 2005). There it was concluded that addressing psychosocial problems might improve diabetes outcomes, but that providers lack the necessary resources for doing so, such as skills, time and adequate referral sources.

Many organisational and environmental factors are known to affect practitioners’ ability to practice, and may prevent successful implementation of patient-centred and individualised care. Pressure of time and lack of continuity are known constraining factors (Rogers et al., 2005), and recognised by my co-researchers, who described their visits to the clinic as impersonal at times, like being on a ‘production line’.
The resolution of the dilemma between respecting autonomy and the beneficence role, demands open and honest discussion among healthcare professionals. Gadamer (1994) says that practice is the presentation of self, that one’s actions and words reflect who one is. Within the resolution lies the risk of demonstrating only what Beauchamp and Childress (2001) call respectful attitude and not respectful action. Thus a change in practice begins within each practitioner who must question own values, goals, intentions and attitude towards patients and realise that a grey area exists between beneficent encouragement, coercion and manipulation (Tomkowiak and Gunderson, 2004). Another risk lies in changing terms and ideology (such as the shift from using ‘compliance’ to ‘adherence’), but retaining the same unchanged intention of making patients do what we want them to do. Authors like Powers (2003) and Árnason (2003) warn against this pitfall. The use of terms such as ‘empowerment’, ‘advocacy’ or ‘consultation’ to achieve a predetermined outcome is a coercive strategy. Using those terms may be more ‘politically correct’, but to be authentic they must truly and honestly be rooted in respect for the patient’s autonomy. Such a ‘commitment to honour people’s choices’ (Bournes, 2000) may not be as easy as it sounds. It means that healthcare professionals must witness suffering that they believe was preventable; they may experience feelings that their professional expertise is being ignored, and they may have to question their own professionalism: have they fulfilled their ethical obligations sufficiently in the relationship?

My co-researchers portrayed a picture of people who need different kinds of help. While some wanted simple advice others wanted decisions made for them. Still others needed dialogues and discussions in order to be able to make informed and independent decisions. Some expressed a very limited need for any relationship, which raises the question: is this a result of poor relationships over the years, or is it possible that some people need only a relationship similar to the ‘consumerism’ described above? Árnason
(2003) notes that within the resolution of authentic dialogues, the professional shows the patient respect by criticising his or her values and opinions if they conflict with his or her (assumed) interests, appealing to the patient’s ‘freedom of choice’, judgement and responsibility. Thus autonomy can be nurtured by developing arguable values that can change, with time, in dialogues with others, such as healthcare professionals (Árnason, 2003). In this way communication becomes a vehicle for sharing information and values (Erlen, 1997); it is an ethical obligation in order to prepare patients sufficiently for their self-management role (Redman, 2005) and a prerequisite for patients to be able to understand how their disease affects their condition and health.

6.3 Limitations and strengths of the study

6.3.1 Limitations

Some unforeseen developments defined limitations to the study. These have been acknowledged:

- Type 1 diabetes gives no option of totally neglecting the treatment regimen, unlike many other chronic conditions, such as type 2 diabetes. This may have affected the findings.
- The question remains of the study’s trustworthiness: do the findings portray the experience of adherence and not just general life with diabetes? This question could be answered by conducting similar studies with the participation of people with other diseases than diabetes.

6.3.2 Strengths

The recognised strengths of the study are:

- Heterogeneous sample in regard to demographics and experience which yielded both typical and atypical descriptions.
• Good quality data: all the co-researchers were very articulate and willing to talk about their experience. Sixteen dialogues should provide ample data, considering the quality of the co-researchers and the duration of the dialogues.

• My own distance from the subject: I assume that I was more open to my co-researchers’ experience than I would have been if I had been more accustomed to diabetes care, as a diabetes educator for example. This may have strengthened the study.

6.4 Implications and recommendations for practice

The findings of the study have raised several questions about healthcare services, the curriculum of healthcare professionals, the philosophy underpinning their practice, as well as some ethical considerations. My suggestions for practice, based on these findings, are not limited entirely to nursing, as I find them relevant to all healthcare professionals that prescribe treatment regimens to patients:

• Healthcare professionals need to start questioning their own attitudes, values and goals of practice. The study raises many fundamental questions about healthcare, and these could be explored within the professions.

• Attitudes towards adherence issues as well as own role in healthcare are moulded in professionals’ training. I suggest that the concept of adherence should be discussed more within the curriculum. Inviting patients to participate in such discussions could be an effective learning experience for both parties.

• Out-patient services: The findings suggest that a wider range of services could better meet patients’ needs. ‘Drop-in’ access to out-patient clinics (no appointment needed), might help those who face immediate difficulties. More flexibility in the services could consist of longer consultations for some, while others could make more use of electronic resources such as e-mail, chat-channels
and information on websites. This would save time and travel for some people, and leave more time for others. Lack of continuity in care and time constraints are organisational factors that could be changed. Offering psychological assistance might improve services.

- Within primary healthcare lie opportunities to improve services. People, especially in rural areas, could be assisted in forming self-help groups, if they wish. Primary healthcare could take over routine check-ups of people who are managing well, referring those with difficulties to specialists. Information technology offers new opportunities in communication, especially in rural areas and could improve services, between patients and providers, GP’s and endocrinologists, nurses in primary healthcare and diabetes educators (nurses), dieticians and other specialists in diabetes care. Thus distribution of services could be more individually designed.

- **Nursing:** Encounters with nurses were rare for my co-researchers met nurses. Nurses’ role in diabetes care needs to be better defined, and their ability and working environment strengthened in order to make them better able to fulfil that role. More positions for specially-trained nurses in out-patient clinics and primary care could meet the needs for continuity and individually tailored care.

- Healthcare staff who are not diabetes specialists, know very little about diabetes and its management, according to my co-researchers. Their textbook knowledge is frequently inappropriate in real-life situations and patients may feel very insecure in their hands. This should be considered within the healthcare system.

### 6.5 Suggestions for further research

Patients’ perspectives are rarely addressed in adherence research. My findings give ample reason for continued research in order to improve understanding of adherence and life with chronic illness. My suggestions for future research include:
• Similar phenomenological studies with participation of people with other chronic diseases than diabetes.

• Phenomenological studies exploring adherence from healthcare providers’ perspectives and comparing them with patients’ perspectives.

• Intervention studies exploring the effect of a model of care based on collaboration, and which uses other indicators than biomarkers to evaluate successful adherence. Such studies could be conducted in relation to the proposed development and reorganisation of out-patient clinics within the National University Hospital.

• Intervention study addressing the effect of self-help groups on wellbeing and self-management as evaluated by diabetes patients.

• Study that addresses healthcare professionals’ attitudes towards patients and how they communicate in real life with patients.

• Studies evaluating how well-equipped healthcare professionals are in providing psychosocial support to diabetes patients.

• Intervention studies aimed at assisting patients with identifying their own unique body cues associated with hypoglycaemia, euglycaemia and hyperglycaemia.

• Adherence difficulties started frequently in adolescence. Intervention studies aimed at young people might provide basic information that could support effective self-management in adulthood.
Chapter 7

Conclusion

This study, guided by hermeneutic phenomenology, has provided insight into life with diabetes and the restrictions imposed on that life by prescribed treatment regimen. Furthermore, it has portrayed how much impact healthcare professionals’ attitudes can have on people, either for good or worse.

Exploring the experience of adherence within phenomenological philosophy has changed the meaning of the concept for me; from a problem to be solved, to being a question of ethical practice. Furthermore, it has enhanced my understanding of people with diabetes, for them, adherence is part of ‘being in the world’.

The study revealed how people with diabetes exist in the world, in interaction with healthcare professionals and others and strive to gain meaning from the experience of being diagnosed with a disease, of being ill, of being embodied in an ever-unpredictable and changing body. Their interpretations and understanding of living with an unfitting treatment regimen differ from the perspectives of others, predominantly the healthcare professionals who are appointed to their medical and nursing care, and this difference leads to conflict. The concepts of temporality and spatiality help in understanding how the lived experience of adherence is dependent on time and space. Issues such as quality of life relate to situatedness; will the treatment regimen give ‘years to life or life to years?’ How is health defined and what behaviour does society expect from us? How is language used when a treatment regimen is prescribed and promoted, and what are the implications (if any) of the non-existence of the word ‘compliance’ or ‘adherence’ in the Icelandic language? What about situated freedom? People choose and are responsible for their choices. These phenomenological concepts are interwoven in my study and create new exciting research questions.
I conclude that the ‘problem’ of non-compliance or non-adherence belongs to healthcare professionals and society, those who initially created the term. Like a boomerang, it seems to have returned to strike those who threw it, insisting that its solution lies with themselves.

For the person with diabetes, the main issue is to simultaneously manage to take care of oneself and the disease, with the ultimate goal of integrating the two. The success and responsibility of doing so belongs to that person, but supportive healthcare professionals, within a supportive healthcare system, can enable or disable this lifework.

Ethically and professionally, healthcare professionals are obliged to fulfil that role as best they can. While patients strive to find balance between life and disease, healthcare professionals should strive to find similar balance in their encounters with patients, between extreme beneficence (paternalism) and extreme autonomy (‘consumerism’).

Instead of labelling patients as ‘difficult’, ‘irrational’ or ‘in denial’, and thus a problem, we should embrace the challenge they constitute for us as practitioners, and aim at the outcome of patient satisfaction with our care instead of the traditional predetermined outcome of certain levels of biomarkers.

If patients receive the message that they are only welcome when everything is under control, because we can only deal with adherent, ‘good’ patients, what will the consequences be? And where does the responsibility then lie?
Appendix 1 (Certification of translation)
Appendix 2 (Advertisement for participants for the study)
Translated from the original by Anna H. Yates

Are you willing to share your experience of living with diabetes?

The undersigned is looking for participants in a study of the experience of living with and seeking to follow complex treatment regimens for diabetes.

Participants must be at least 18 years old, have been diagnosed with diabetes for at least 3-5 years, and use blood-sugar monitoring and insulin injections as part of their treatment. They must have experience of following and/or not following the instructions or guidance they have been given by doctors, nurses and/or dieticians, and must be prepared to share that experience with the researcher.

The study has been approved by the Bioethics Committee, and has been notified to the Data Protection Authority as required by law. Participation in the study is entirely without obligation, and participants may withdraw at any time.

If you are interested in knowing more, please contact me as soon as possible!

With kind regards

Brynja Ingadóttir
Nurse
Tel. 562-5934, 865-1817
e-mail: brynjain@operamail.com

This study is for my dissertation for the degree of MSc in nursing at the Royal College of Nursing Institute/Manchester University in Britain in co-operation with the University of Akureyri, Iceland.
Appendix 3 (Introductory letter and informed consent, page 1)

Translated from the original by Anna H. Yates

UNIVERSITY OF AKUREYRI
Reykjavík, xx, 2005

Dear ......

Thank you for taking an interest in my research project on the experience of living with and seeking to follow complex treatment regimens for diabetes.

I am studying for an MSc degree in nursing at the Royal College of Nursing Institute/Manchester University in Britain in co-operation with the University of Akureyri, Iceland.

I enclose two copies of the same letter. These comprise two parts: information on the study, and consent for participation in the study. Please read the letter carefully. If you decide to take part in the study please sign and date the letter of consent and send it to me (all three pages) in the enclosed stamped addressed envelope. The other copy of the letter is for you to keep. Soon after I have received your consent I will be in touch with you.

You are welcome to contact me if anything about the study is unclear, or if you wish to discuss it further with me. My phone number, e-mail and address are shown below.

With regards

Brynja Ingadóttir
Researcher
Þórsgötu 17, 101 Reykjavík
Tel 562-5934, 865-1817 e-mail: brynjain@operamail.com

Professor Sigríður Halldórsdóttir
Research supervisor
Faculty of Health Sciences, University of Akureyri
Tel. 463-0900/91 (direct phone), e-mail: sigridur@unak.is
Appendix 3 (Introductory letter and informed consent, page 2)

Information

Title of study
‘Adhering and/or not adhering to treatment prescriptions for diabetes, and the consequences of this for the relationship between patient and healthcare professionals’.

Researcher
Brynja Ingadóttir
BSc Nurse, MSc candidate
Unit Manager at the Heart- Lung and Eye Surgery Ward
Landspitali – University Hospital
Reykjavík

Research supervisor
Professor Sigríður Hallórsdóttir, RN, MSN, PhD (Med. Dr)
Faculty of Health Sciences, University of Akureyri
Sólborg v/Norðurslóð
600 Akureyri

Description of study: Diabetes is a chronic disease, whose incidence is fast increasing all over the world. Research has demonstrated the importance of maintaining blood-sugar within certain limits in order to reduce the likelihood of the many serious complications of the disease. In order to maintain blood-sugar within appropriate limits, various forms of treatment are prescribed for patients, such as medication in tablet form and/or insulin injections, special diet and physical exercises. Healthcare staff expect adherence from the patient, because adherence to the treatment relates to control of blood-sugar, the ultimate aim of the treatment. The viewpoint of the patient, and the experience of living with and following these prescriptions, has received less attention, as has the situation when prescriptions are not followed.

The objective of this study is to gain understanding of this experience. What is it like to live with treatment prescriptions for diabetes, and what does it mean in everyday life? What happens in interaction with doctors, nurses or dieticians when you do not follow the treatment? I am interested in finding the answers to these questions, which have arisen in
Appendix 3 (Introductory letter and informed consent, page 3)

my relations with patients who are dealing with following treatment while living a normal daily life.

The participants in the study are individuals with diabetes, aged 18 and over, who have been diagnosed with diabetes for at least three years, and use blood-sugar monitoring and insulin injections as part of their treatment. They have experience of following and/or not following the treatment prescriptions they have been given. The intention is that about 10 people participate in the study,

**Method:** This study is guided by phenomenology, and the findings will be analysed by the method of the Vancouver School of doing phenomenology. Phenomenology explores people’s experience and its meaning for the individual, with the aim of improving understanding (for instance by healthcare staff). The method sees the participants as co-researchers, and the participant and the researcher, you and I, will explore together what ‘adherence’ really means. Data collection will take place between us two. The dialogues will be audiotaped, and then transcribed onto computer by me.

**What does participation entail?** As a participant in the study, you must have experience of following and/or not following treatment prescriptions for diabetes, and be ready to discuss that experience. One dialogue is expected to be sufficient for data collection, but I may request another interview if necessary. The dialogue will take about one hour, and can take place wherever you wish, for instance in your home or at my office.

Taking part in the study can be beneficial, as discussion of one’s own experience can improve one’s understanding of one’s circumstances. Participation does not entail any perceptible risk, although it is possible that discussing your experience could be upsetting for you. If after our dialogue you need to discuss this further with someone not connected to the study, you are welcome to contact Nurse Anna Dagný Smith (tel. 820-3360), e-mail annad@sagaheilsa.is), who will be happy to talk to you.

**Consent and permits**

This research project has been approved by the Bioethics Committee, and has been notified to the Data Protection Authority as required by law.
Appendix 3 (Introductory letter and informed consent, page 4)

Informed consent

I hereby consent to take part in the study ‘Adhering and/or not adhering to treatment prescriptions for diabetes, and the consequences of this for interaction between patient and healthcare professionals’, to be carried out by Nurse Brynja Ingadóttir.

I have been given information on the study, see attached information letter, and I understand that:

- I must be at least 18 years old.
- I participate freely, and I can withdraw from participation without any explanation at any stage, without any consequences for other treatment.
- All information I give about myself or audio-taped about me during my participation will be used only for the purposes of the study.
- All information I give about myself or audio-taped about me during my participation is confidential and will be kept in a secure place.
- I may refuse to answer questions, and I may also request that information on tape be erased.
- A summary from a dialogue and direct quotations may be included in the dissertation, but only in such a manner that I cannot be identified.
- Audiotapes from the dialogue will be labelled with a pseudonym. They will be destroyed by the researcher when the study has been concluded.

Place___________________ Date___________

_______________________
Co-researcher (participant)

_______________________
Researcher
Brynja Ingadóttir
Þórgötu 17, 101 Reykjavik
Tel. 865-1817. 562-5934  e-mail: brynjain@operamail.com

Research supervisor
Professor Sigridur Halldórsdóttir
Faculty of Health Sciences, University of Akureyri, 600 Akureyri
Tel. 463-0900  e-mail: sigridur@unak.is

If you have any questions about your rights as a participant in scientific research, or if you wish to withdraw from participation in the research, you can contact the Bioethics Committee, Vegmúli 3, 108 Reykjavik. Tel: 551-7100, fax: 551 1444
Appendix 4 (Correspondence and clearance from the Bioethics Committee, page 1)
Translated from the original by Anna H. Yates

University of Akureyri, Faculty of Health Sciences
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602 Akureyri

BIOETHICS COMMITTEE
Vegmúli 3, 108 Reykjavik
Tel. 551 7100, fax 551 1444
e-mail:

Reykjavík, 26 October 2004
Ref. VSNb2004100002/03-7 Námsverkefni-nemaransóknir almennar/BH/--

Re: 04-114-afg Adhering and/or not adhering to treatment prescriptions for diabetes, and the consequences of this for interaction between patient and healthcare staff: a phenomenological study

At its meeting of 12.10.2004 the Bioethics Committee considered your application dated 05.10.2004 with regard to the above-mentioned research plan. Your co-researcher is Brynja Ingadóttir, Unit Manager at Landspítali – University Hospital, the research is her study project.

The objective of the project is to explore the phenomenon of treatment adherence on the basis of the experience and viewpoint of the patient who is expected to adhere to the treatment. In dialogues with diabetes patients who have experience of either adhering or not adhering to the treatment regime, an effort will be made to analyse those factors which are characteristic for this experience, with the purpose of improving healthcare staff’s understanding of the phenomenon. The value of the project lies in adding to the knowledge base on adherence, and in presenting a viewpoint which has hitherto been little studied.

The participants will be chosen by purposeful sampling, and they are estimated to number about 10. Individuals will be chosen who are Icelandic-speaking Icelanders, 18 years old and older, who have been diagnosed with diabetes and used insulin in their treatment for at least 3-5 years.

If the individual contacts the researcher after seeing an advertisement, or if the researcher receives permission to contact a prospective participant, the individual will be given information on the study by phone. If the individual agrees to consider participating, the researcher will send by mail an information sheet on the study, and an informed-consent form, which the person in question is requested to sign, thus granting consent for participation in the study.
The Bioethics Committee has the following observations on the research plan:

1. The Bioethics Committee requests information on the dialogue framework which the researchers plan to use in the study.

2. The Bioethics Committee request to be sent a copy of the collaboration declaration from Anna Smith, who is to be available to participants if necessary.
3. The Bioethics Committee requests that the supervisor of the study sign the information sheet to participants, together with the co-researcher.

4. The text of the informed consent sheet correctly states that the individual can decline to participate in the study. The Bioethics Committee requests that after that sentence the following be added: "without consequences for other treatment."

5. The Bioethics Committee feels that it would be desirable, in the advertisement for participants in study, to include an e-mail address to which queries could be addressed.

The study will be considered for final approval within the Bioethics Committee when it has received answers to the above points. Information on deadlines is available on the Committee's website [www.visindasidanefnd.is](http://www.visindasidanefnd.is)

Please note that it is not permissible to commence carrying out the study until the Bioethics Committee’s final consent has been granted.

**On behalf of the Bioethics Committee**

**Regards**

*(signed)*

Björn Guðbjörnsson, chair.
Appendix 4 (Correspondence and clearance from the Bioethics Committee, page 3)

Bioethics Committee  
Vegmúli 3  
108 Reykjavik  

Reykjavík, 25 November 2004

The undersigned thanks for the Bioethics Committee’s letter dated 26 October last with regard to the application for consent for the study “Adhering and/or not adhering to treatment prescriptions for diabetes, and the consequences of this for interaction between patient and healthcare staff: a phenomenological study.” My answers to the Committee’s observations are as follows:

1. Information on dialogue framework used in the study: In phenomenological research no dialogue framework as such is used; in the dialogue an effort is made to identify what is characteristic of the experience being studied, and the subject is explored in dialogue with the co-researcher. Thus questions are not prepared in advance. However, the following are examples of questions that the researcher is likely to ask in dialogues with participants in the study:
   - Tell me how you were originally informed about the treatments you were advised to adhere to.
   - Tell me how adhering to treatment prescriptions fits in with other aspects of your daily life.
   - What are the main influences on whether you adhere or do not adhere to treatment prescriptions?
   - How do you feel when you are not adhering to treatment prescriptions?
   - What does the treatment mean to you?
   - What happens in your interaction with healthcare staff when you don’t adhere to their treatment prescriptions?

2. The signed collaboration declaration of nurse Anna D. Smith is appended.

3. The study supervisor signs the information sheet to participants: the letter has been amended, see appended letter.

4. Add to the informed-consent letter “without consequences for other treatment.” Alteration made, see appended informed-consent form.

5. Add researcher’s e-mail to advertisement for participants in the study: This has been done, see appended advertisement.

Regards

Brynja Ingadóttir
Appendix 4 (Correspondence and clearance from the Bioethics Committee, page 4)

BIOETHICS COMMITTEE Vegmúli 3, 108 Reykjavík Tel. 551 7100, fax 551 1444 e-mail: visindasidanefnd@vsn.stjr.is

University of Akureyri,
Faculty of Health Sciences
Professor Sigríður Halldórsdóttir, RN, MSN, PhD
Sólborg v/Norðurslóð PO box 224
602 Akureyri

Reykjavík, 7 December 2004

Ref. VSNb2004100002/03-7 Námsverkefni-nemaranssóknir almennar/BH/--

Re: 04-114-S1 Adhering and/or not adhering to treatment prescriptions for diabetes, and the consequences of this for interaction between patient and healthcare staff: a phenomenological study

The Bioethics Committee thanks you for your letter of reply dated 25.11.2004 in response to observations previously made regarding your above-mentioned research proposal, see the committee’s letter dated 26.10.2004. The letter contains answers and explanations in accord with the Bioethics Committee’s observations.

The letter was accompanied by a new and improved letter of information and consent for participants in the study, and finally a copy of a collaboration agreement dated 25.11.2004, signed by Anna Dagný Smith.

Your letter of reply and other documents submitted were discussed at a meeting of the Bioethics Committee of 07.12.2004, and they were deemed satisfactory.

Your research proposal is granted final approval by the Bioethics Committee.

The Bioethics Committee requests that researchers quote the VSN reference number of the study when reference is made to the committee’s approval in published papers on the study. The Bioethics Committee also requires to be sent copies of published papers on the study. Researchers are reminded to notify the committee when the study is completed.

Regards
On behalf of the Bioethics Committee
Bryndís Valsdóttir, deputy manager
Appendix 5 (Clearance from the Data Protection Authority)
Translated from the original by Anna H. Yates

Data Protection Authority
Rauðarárstigur 10, 105 Reykjavík
Tel. 510 9600  Fax 510 9696
e-mail: postur@personuvernd.is
website: personuvernd.is

Sigríður Halldórsdóttir
Steinahlíð 8a
603 Akureyri
Reykjavík, 8 February 2005
Ref. S2352/2005/EB/-

It is hereby confirmed that the Data Protection Authority has received notification in your name of processing of personal data. The notification has been assigned the reference number S2352/2005, and a copy of it is attached.

All notifications sent to the Data Protection Authority automatically appear on the Authority’s website. It is pointed out that by receipt and promulgation of the notification, the Authority is not expressing any view on the content.

Sincerely

Erla Björgvinsdóttir
Appendix 6  (Collaboration agreement)
Translated from the original by Anna H. Yates

Collaboration agreement

I, the undersigned, Nurse Anna Dagný Smith (ID no. 090663-4379), hereby confirm that I have agreed to assist participants in Brynja Ingadóttir’s study ‘Adhering and/or not adhering to treatment prescriptions for diabetes, and the consequences of this for interaction between patient and healthcare staff’ if necessary during the study or after they have participated in it.

Reykjavik, 25 November 2004

____________________
Anna Dagný Smith (sign)


Bibliography


