Diabetes-Related Blindness

Studies of Self-Management, Power, Empowerment and Health

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Abstract

Individuals with diabetes and blindness meet problems in daily life that are related to both conditions. The aim was to study diabetes self-management, burden of diabetes, power, sense of coherence (SOC) and health among individuals with diabetes-related blindness. The aim was further to determine psychometric properties of a diabetes empowerment scale (DES) and to use it in the evaluation of an empowerment programme. The participants were 39 blind diabetic and non-diabetic individuals and 21 diabetic individuals with threat of blindness. A convenience sample of 195 diabetic patients completed DES and 9 blind diabetic individuals participated in the empowerment programme. Two reference groups from the Swed-qual population studies were also included. Data were collected by questionnaires, interviews and by scrutinizing medical records. Quantitative data were analyzed with parametric and non-parametric methods and qualitative data with content analysis. Blind diabetic individuals expressed more problems with self-management than did those with threat of blindness. In some health domains, blind diabetic individuals perceived significantly poorer health than did non-diabetic blind individuals. There were though individual differences in how blind individuals perceived their health as well as how burdensome they experienced their self-management. Individuals with power and strong SOC felt less burden and perceived better health when compared to those with weak SOC or non-power. The diabetes empowerment scale showed acceptable validity and reliability and was used, along with qualitative interviews, to evaluate the effect of the empowerment programme. Evaluation of the programme showed that the participants had improved knowledge and awareness of self-management. The programme seems suitable for blind individuals and creates an inspiring learning climate enhancing empowerment. It is concluded that blind individuals have problems in their diabetes self-management and perceive poor health but the experience of power is a factor of importance for health and an empowerment education programme may enhance power.

Keywords: Diabetes mellitus, Blindness, Power, Empowerment, Health

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IV. Leksell, Janeth; Funnell, Martha; Sandberg, Gun; Smide, Bibbi; Viklund, Gunnel & Wikblad, Karin: Psychometric properties of the Swedish Diabetes Empowerment Scale (In progress)

V. Leksell, Janeth; Sandberg, Gun & Wikblad, Karin: Experiences of an educational programme for individuals with blindness caused by diabetes (In progress)

Reprints of papers I-III were made with permission from the publishers.
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Introduction

In an ongoing longitudinal study, we have found a relationship between the presence of late complications and low self-perceived health. One group in particular that developed blindness due to diabetes retinopathy experienced poorer health in comparison with sighted diabetic individuals (Wikblad et al., 1996).

Diabetes Mellitus

Diabetes mellitus encompasses a worldwide health problem. Almost 140 million people suffer from diabetes and this number is estimated to be doubled by 2025 (Amos et al., 1997; WHO, 1999; Zimmet, 2000) In Sweden, 3-4 % of the population, approximately 300.000 individuals, are known to have diabetes (Socialstyrelsen, 2000).

Diabetes Mellitus is a group of metabolic diseases caused by inherited and/or acquired deficiency in insulin produced by the pancreas, or by ineffective uptake of the insulin produced.

Insulin deficiency results in high blood glucose, which in turn over time may result in micro- as well as macro-vascular late complications. The most common micro-vascular complication before the age of 65 is diabetic retinopathy (Malone et al., 2001; Toeller et al., 1999).

Diabetic retinopathy and blindness

From the patients’ point of view, diabetic retinopathy might be the most frightening scenario as it may lead to blindness (Watkins, 2003). There are three stages of retinopathy: background, preproliferative and proliferative (Watkins, 2003). Mostly, there are no symptoms or pain in the early stages (background or preproliferative retinopathy). Vision may not change until the retinopathy becomes severe. Growth of new blood vessels, known as proliferative retinopathy, may lead to blindness through haemorrhage and scarring (Gargiulo et al., 2004). Fundus photography is needed to check for signs and to diagnose retinopathy (Agardh, 2002; Agardh, 2005; Klein, 2002). A difference in the prevalence of diabetic blindness is present in comparisons of populations that have been involved in systematic screening.
programs (fundus photography) with those not involved (Agardh, 2005). Already twenty years ago, the Diabetic Retinopathy Study Research Group (1981) reported that panretinal photocoagulation is an effective way of reducing the risk of blindness in patients with proliferative retinopathy.

International clinical guidelines from the International Council of Ophthalmology suggest that regular screening should be performed every second year for all diabetic individuals (Sommer et al., 2003; Spivey, 2001). European guidelines suggest that regular screening starts already at puberty (Younis et al., 2003). In Sweden, the National Board of Health and Welfare has suggested regular screening for retinopathy every second year for all diabetic individuals beginning at the age of ten years (Socialstyrelsen, 2000).

Many people with diabetes will develop some degree of diabetic retinopathy during their lifetime. In the Wisconsin studies from 1994 (Klein et al., 1994) and 1998 (Klein et al., 1998), the 10 and 14-year progressions of retinopathy were reported to be 76% (after 10 years with diabetes) and 86% (after 14 years), and progression to proliferative retinopathy 30% and 37%, respectively (Klein et al., 1994; Klein et al., 1998b). The prevalence of legal blindness, i.e. a visual acuity (VA) ≤0.1 in the best eye has been found to be between 2.3% and 7.9% (Agardh et al., 1993; Sjolie et al., 1997). Blindness in a diabetic population on Iceland was found to be 2.4% in 1980, and in 1994 after a systematic screening program, the frequency had decreased to 0.5% (Stefansson et al., 2000). This is in accordance with results from a Swedish study in which the reduction in incidence of blindness decreased by one-third over a twenty-year period from 1975 to 1995 (Bäcklund et al., 1997).

Results from the Diabetes Complications Clinical Trial (DCCT) (1995, 2000) showed that strict glucose control might delay the onset and progression of complications in type 1 diabetes. Besides poor glycaemic control, risk factors for developing diabetic eye disease are long diabetes duration and high blood pressure (DCCT, 1995; 2000; Klein, 2002).

One of the important goals of diabetes care is to achieve good glycaemic control. This is also an essential goal for those who have already gone blind due to diabetes, to prevent the development of other late complications such as neuropathy, nephropathy and macro-vascular disease (myocardial infarction or stroke). Thus, it is important to find ways to assist the blind diabetic individual to manage daily life.

Diabetes self-management

A number of problems in diabetes self-management are a reality for diabetic individuals. For those with the combination of diabetes and visual disability, daily life implies even more difficulties (Bernbaum et al., 1988a; Bernbaum et al., 1993; Williams, 2002). These people must deal with stresses related to
the disease of diabetes, such as preparing and taking insulin and monitoring blood glucose, as well as managing practical problems (Williams, 2002). Glasgow and Eakin (2000) have structured the concept of self-management in three various components; self-management influences, self-management behaviours (or activity) and self-management consequences. Self-management influences’ include cognitive factors (e.g. knowledge related to diabetes and its treatment), affective factors (e.g. motivation, self-awareness, emotional mood, readiness to change, flexibility) and social support from relatives and health-care professionals. These factors could either facilitate or obstruct ‘self-management behaviour’ (Delamater et al., 2001; Devries et al., 2004; Rubin et al., 2004) which consists of self-management skills such as self-adjustment of insulin doses, monitoring blood glucose and knowing how to interpret the result. The third component, ‘self-management consequences’, consists of outcomes, such as glycaemic control and self-perceived health. Glasgow and Eakin (2000) are of the opinion that other factors, such as the development of late complications or other co-morbidity, influence the individual’s self-management.

Diabetes self-management and self-perceived health

In 1999, Rubin and Peyrot performed a literature review focusing on how different aspects of self-management are related to self-perceived health among adults with diabetes. They pointed out that “certain disease and demographic characteristics may powerfully affect quality of life in people with diabetes, while diabetes per se may not” (aa.p.121). The authors found that diabetic individuals who believed they could manage their diabetes, and who used problem-focused strategies to cope with different problems, perceived good health. This is in accordance with other studies that showed that diabetic individuals use active and problem-oriented coping-strategies more than most other chronically ill patients do. Such strategies have been found to be related to better well being (Graue et al., 2004; Grey et al., 2000; Grey et al., 1997). Other studies have found that diabetic individuals with good understanding of their own condition and treatment and high self-confidence in their self-management (i.e. empowerment) perceived good health (Anderson et al., 1995; Weinger & Jacobson, 2001; Via & Salyer, 1999). Bijl et al., (1999) and McDowell et al., (2005) reported that people who trusted their own potential concerning nutrition, physical treatment and blood sugar were satisfied with their own health. These studies also indicated that individuals who are more actively involved in their self-management might be more likely to perceive better health. The association between self-management behaviour and self-perceived health is complex. The results from the DCCT study (Keen, 1994) showed that treatment intensification has an uncertain effect on self-perceived health. This means that a change from twice-daily
insulin injection to multiple insulin injection did not deteriorate self-perceived health (Keen, 1994). Glasgow et al., (1999) suggested that such intensification improved self-perceived health by reducing acute and long-term complications of hyperglycaemia. Wredling et al., (1993) found that intensification of treatment resulted in a higher frequency of hypoglycaemia, which in turn led to decreased self-perceived health (Davis et al., 2005; Lloyd & Orchard, 1999; Wikblad et al., 1996). Fluctuating blood glucose levels have been reported to be associated with decreased self-perceived health (Johansson, 2000). Few studies have examined the association between self-monitoring of blood glucose and self-perceived health. Wredling et al., (1995) did not find any association between frequency of self-monitoring and well being in her 1995 study.

In a literature review, Rubin and Peyrot (1999) found that the relationship between glycaemic control and self-perceived health (i.e., self-management consequences) was not clear. However, in a Swedish study diabetic individuals with acceptable glycaemic control perceived better health compared to those with good or poor glycaemic control (Wikblad et al., 1996). In one aspect, the review by Rubin and Peyrot (1999) and the study by Wikblad et al., (1996) were consistent. Both studies found that the presence of two or more diabetic late complications was associated with poor self-perceived health.

Few studies have evaluated self-perceived health among individuals with the combination of visual impairment and diabetes. They have focused solely on the psychosocial aspects of visual impairment, but have not examined other aspects of self-perceived health (i.e. physical and social functioning) (Bernbaum et al., 1988 b; Cox et al., 1998; Wulsin et al., 1993). Wulsin et al., (1993) found moderate correlation between worsening visual acuity and worsening psychological symptoms, such as depression, in a sample of individuals with diabetes retinopathy. Bernbaum et al., (1988b) observed that those with fluctuating visual impairment experienced greater emotional distress and depression than did those with stable visual impairment. Furthermore, Cox et al., (1998) found a higher degree of anxiety, worries and fear among people with visual loss compared to those with fluctuating vision.

Burden of diabetes

Burden of diabetes has been used to describe the epidemiological and economic aspects of diabetes with its late complications (Barcelo et al., 2003; Klein et al., 1998a). At present, there is limited information on how the burden may affect glycaemic control and self-perceived health. Wikblad et al., (1990) suggested that individuals’ views of the burden are influenced by their attitudes regarding diabetes. This deals with their feelings of them-
selves as constrained, weak, worthless, unsafe, tense and/or dependent and viewing diabetes dominant and difficult to handle.

The disease of diabetes constitutes a burden in itself, for example concerning preparation and administration of insulin and self-monitoring of blood glucose. Vision impairment increases the burden essentially, requiring the blind diabetic individual to seek alternative solutions to achieving independence in these activities. It is not always simple to find these alternatives (Bernbaum et al., 1988b). Besides this, during recent years there has been a gradual loss of visual aids for blind diabetic individuals, such as the ‘talking blood glucose meter’. Moreover, these individuals have often been excluded from diabetes educational programmes. Consequently, blind diabetic individuals express a feeling of worthlessness (Williams, 2002).

The burden of diabetes is multifaceted due to other medical problems related to long diabetes duration and the development of other late complications besides retinopathy. A slow gastric emptying (gastroparesis) occurs sometimes in individuals with long diabetes duration (Horowitz et al., 1996) and/or other late complications (Bytzer et al., 2002; Bytzer et al., 2001). Symptoms of gastroparesis may include flatulence, vomiting, early satiation, constipation, diarrhoea and faecal incontinence, but also labile blood glucose with hypoglycaemia and hyperglycaemia (Johansson, 2000). To live with these symptoms and unstable blood glucose make the diabetes dominant and difficult to handle.

Peripheral neuropathy is another late complication that may lead to decreased sensibility/sensitivity in the feet and hands. This makes it difficult to perform physical activity, read Braille with the fingertips and perform blood glucose monitoring. Another burdensome situation is the phenomena of ‘hypoglycaemia unawareness’, which means that diabetic individuals do not notice when their blood glucose is getting low. A feeling of uncertainty might arise and make it difficult to handle daily life. The impact of diabetic retinopathy on daily life has been evaluated (Lamoureux et al., 2004), using the questionnaire ‘The Impact of Vision Impairment’. The results showed that poorer visual acuity was related to different areas in daily life, e.g. restrictions in mobility, work, leisure and social interaction. The limitation in social activities was associated with many difficulties. Blind diabetic individuals were at greater risk for separation than were others (Bernbaum et al., 1993). They also hesitated to use public transports, and felt frustrated and burdensome (Lamoureux et al., 2004).

Meltzer and Egleston (2000) stated that sighted diabetic individuals worried about late complications already before they had occurred. A cross-sectional study from 13 countries in Asia, Australia, Europe and North America reported that diabetes-related worries were common among a majority of diabetic individuals (Peyrot et al., 2005). The questionnaire used in this study included different areas of diabetes-related stress such as worries and anxiety about the future, the risk of hypoglycaemic events and worries
about the disease becoming worse. These emotions might result in inadequate self-management, which increases the physical and emotional burden of diabetes (Glasgow et al., 1999). It is easy to understand why depression is common among diabetic individuals (Karlson & Agardh, 1997; Rubin et al., 2004).

Sense of Coherence

Mastering the burden of diabetes is a lifelong process. It requires an inner ability to handle daily life successfully, and to guard oneself from the negative influence of life stresses (Sigurdardottir, 2005).

Sense of Coherence (SOC), a model developed by Antonovsky, has been described as being useful in bridging the gap between burden and wellbeing (Antonovsky, 1993). The SOC deals with the individuals’ ability to understand the entire situation and their capacity to use resources needed. The three components meaningfulness, comprehensibility and manageability are described as the central parts of the SOC and are measured with items arranged on seven-point Likert scales. When an individual scores high on the SOC he/she is well able to solve problems and take control of his/her life whenever problems occur (Antonovsky, 1993, Eriksson & Lindström, 2005). Individuals with strong SOC, who have suffered from, e.g., myocardial infarction (Moltzer et al., 1996) or cancer (Forsberg & Björvell, 1996) perceived the disease as less burdensome than did individuals with weaker SOC. Within the field of diabetes, a high SOC score has been shown to be related to high degree of acceptance of diabetes (Richardson et al., 2001), lower fear of hypoglycaemia (Shiu, 2004), and higher quality of life (Lundman & Norberg, 1993; Sandén-Eriksson, 2000). No direct relationship between SOC scores and blood glucose levels (HbA1c) in individuals with type 1 or type 2 diabetes has been found (Cohen & Kanter, 2004; Lundman & Norberg 1993; Shiu, 2004).

Power

In nursing the concept of power was developed by Rogers (1970) and Barrett (1998). Barrett (1998) described power as emerging from a shared process of the human and the environment. The interrelation between ‘being aware of what one chooses to do’, ‘feeling free to do’, and ‘doing it intentionally’ constitutes power.

Authors from different disciplines have used the concept of ‘power’ (Barraclough & Stewart, 1992). The social philosopher Michel Foucault (1980) developed power as a philosophical construct, while Gilbert (1995) used the construct to understand the nursing practice: “Nursing and nurses
themselves have to be aware that they and the environment in which they practice, are as much the product of power as are those they claim to support” (p.870).

Other authors have viewed power as an interpersonal construct (Hewison, 1994; Hokanson-Hawks, 1991; Kuokkanen & Leino-Kilpi, 2000; Porter, 1991). Hokanson-Hawks (1991) and Laverack (2005) has analysed power, asserting that power cannot exist unless there is an interpersonal relationship. They both stated that power in the context of health care has two main meanings, ‘power to’ and ‘power over’. ‘Power to’ refers to the ability to achieve goals through an interpersonal process in which the goals are mutually established. ‘Power over’ refers to the ability to get another person to do something he or she would not otherwise have done.

Gallagher (1997) discussed lack of power as a factor in health-defeating behaviour, stating that powerlessness is a ‘third world behaviour’. According to Gallagher, power is the ability to cause change in one’s internal or external environment.

Studies on individuals who have become blind in adulthood deal with dependency and adjustment to the new life situation many years after the onset of blindness (Hudson, 1994; Sanders et al., 1975). It has also been reported that blind adults remain depressed for many years after the onset of blindness (Karlsson, 1998). These studies indicate that the blind individual’s situation could be described as being powerless.

Empowerment

The concept of empowerment has been introduced within recent decades. Empowerment as a concept is abstract and therefore it requires a clear definition describing its significance. It is defined in different ways by several researchers (Freire, 1973; Rappaport, 1987; Zimmerman, 1995). Freire, (1973) formulated the philosophy of empowerment, in which the combination of reflection and action is the key concept. Freire believed that people with experienced trouble can overcome their difficulties through their own critical reflection and action. Later, Rappaport (1987) defined empowerment as “a process by which people, organisations, or communities gain mastery over issues of concern to them” (aa p.135). Zimmerman (1995) suggested that empowerment consists of three components: intrapersonal (e.g., how people think about themselves); interactional (e.g. knowledge and understanding); and behavioural components (e.g. action and adaptation to change).

In diabetes care, Funnell et al.,(1991) asserts that “patients are empowered when they have the knowledge, skills, attitudes and self-awareness necessary to influence their own behaviour and that of others in order to improve the quality of their lives” (aa p.38). In diabetes care, empowerment
involves supporting patients discover and develop their inherent capacities (Funnell & Anderson, 2003; MacKinnon, 2003).

In order to evaluate the importance of empowerment it is necessary to develop instruments and test their reliability and validity.

The Diabetes Empowerment Scale (DES) is one such instrument. The first version was a 37-item questionnaire including eight subscales; ‘satisfaction and dissatisfaction related to living with diabetes’; ‘identification and achievement of personally meaningful goals’; ‘application of systematic problem-solving process’; ‘coping with emotional aspects of living with diabetes’; ‘stress management’; ‘appropriate social support’; ‘self-motivating’ and ‘cost/benefit decisions regarding behaviour changes’. The evaluation of this version implied that the authors reduced the questionnaire from 37 to 28 items and three subscales emerged: ‘managing psychosocial aspects of diabetes’; ‘assessing dissatisfaction and readiness to change’; and ‘achieving diabetes goals’. (Anderson et al., 2003; Anderson et al., 2000)

The DES scale has also been translated and validated to the Chinese language (Shiu et al., 2005; Shiu et al., 2003).

Sense of coherence, power and empowerment in reducing burden of diabetes

Diabetes and blindness is a burdensome combination that probably demands a strong sense of coherence (SOC) and power in the individuals. It seems therefore reasonable to support an individuals SOC and/or power. Laverack (2005) suggested that power can not be given to people but, must be gained or seized by them. One way to support individual to gain power is through appropriate patient education Laverack (2005).

Studies have shown that educational programmes do not necessarily lead to successful diabetes management or improved good metabolic control (Ellis et al., 2004; Norris et al., 2002; Snoek & Visser, 2003; Wikblad, 1991). The huge volume of literature on patient educational programmes indicates that some factors are more important for successful education than others. One factor that seems important is a theoretical framework. In a meta-regression analysis, Ellis and co-workers (2004) found that teaching methods based on a cognitive framework, for example problem-based learning, were most effective in improving glycaemic control. Despite the growing interest in diabetes educational programmes, little attention has been paid to education to blind diabetic individuals (Bernbaum & Albert, 1996).

Furthermore, with the philosophy of empowerment as a basis, an educational programme for individuals with both diabetes and blindness was developed at the St Louis University Medical Centre. The 12-week programme included diabetes skills and strategies, a modified low-level exercise pro-
gramme, psychosocial support groups, and an evaluation of individuals’ glycaemic control. The evaluation showed that the programme resulted in improvement of independent self-management for non-sighted individuals (Bernbaum et al., 2000).

Anderson et al., (1995) used a randomised design to evaluate an empowerment educational programme in the general diabetic population. Individuals are viewed as active participants, setting their own self-management goals and being held responsible for their lives. The content of the programme therefore did not focus on diabetes as such, but on living with diabetes (Funnell & Anderson, 2003). The programme was organized as six 2-hour group sessions offered weekly over the course of six weeks. Each session involved the following topics: “1) enhance the ability of patients to identify and set realistic goals; 2) apply a systematic problem-solving process to eliminate barriers to achieving those goals; 3) cope with circumstances that cannot be changed; 4) manage the stress caused by living with diabetes; as well as the general stress of daily life; 5) identify and obtain appropriate social support; and 6) improve their ability to be self-motivated” (Anderson et al., 1995, p. 944). The evaluation showed that the programme resulted in improvement in both psychosocial health and blood glucose levels.

A similar educational programme has been developed in Sweden. The empowerment programme ‘I’m the boss’ was implemented as group education (Wikblad et al., 2004). Problem-based learning (PBL) was used as the educational method and included six three-hour long weekly sessions. PBL is an eight-step process involving the participants solving a problem that has been formulated by them. The solutions to the formulated problems can be found through literature, by asking an expert, through one’s own reflection and/or other resources. The topics of the six weekly sessions were life satisfaction and goal setting, problem solving, coping with emotions, coping with daily stress, social support and motivation. This programme has been modified according to the evaluation and positive results have been found in a randomised controlled multi-centre study.
Aims of the thesis

The aims of this thesis were to:

- Study some aspects of diabetes self-management and self-perceived health among individuals with diabetes-related blindness and diabetic individuals who experienced threat of blindness. (Paper I)
- Explore perceptions of power in blind diabetic and non-diabetic individuals and relate presence or absence of power to self-perceived health. (Paper II)
- Study relations between sense of coherence and power and their connections to self-perceived health, burden of diabetes, diabetes self-management and glycaemic control (Paper III)
- Determine psychometric properties of the Swedish version of the Diabetes Empowerment Scale (Swe-DES-23). (Paper IV)
- Evaluate whether and how an empowerment programme inspired the participants in developing self-management skills. (Paper V)
Methods

Design
Descriptive and comparative designs were used in Papers I-III. The design for Paper IV was a psychometric testing. The study design for Paper V was an empowerment educational intervention, 'I'm the Boss', with pre- and post measures using both quantitative and qualitative methods for the evaluation.

Samples
Different samples were included in the current thesis. Table 1 presents an overview of the samples used in Papers I-V. One sample comprised individuals with acquired blindness with and without diabetes. The other sample consisted of individuals under threat of becoming blind due to diabetes proliferative retinopathy. The third was a convenience sample of diabetic individuals and the fourth contained blind diabetic individuals participating in the educational programme. In addition, two age- and gender-matched reference groups for self-perceived health were used for comparisons in Papers I and II.

Table 1. Samples in Papers I-V

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Individuals with acquired blindness (Papers I-III)

Individuals with diabetes-related blindness (Papers I-III)
At three adjacent ophthalmic outpatient clinics (Uppsala, Örebro and Falun) 26 individuals with diabetes-related blindness (vision ≤0.1) born between 1939 and 1959 were registered. Twenty-three of the 26 individuals agreed to participate in the study. The mean age of the 23 participants (15 males and 8 females) was 47.4 years (SD±7.6), duration of diabetes was 38.7 years (SD±6.6) and duration of blindness was 13.6 years (SD±4.6).

Individuals with blindness caused by reasons other than diabetes (Papers II and III)
At the same ophthalmic outpatient clinics as the group of blind diabetic individuals, an additional 19 blind individuals were registered. These individuals had developed blindness for reasons other than diabetes, such as optic nerve or corneal atrophy (n=6), tumour (=3), accident/trauma (n=3), glaucoma (n=2), detachment of the retina (n=2), trachoma (n=1), and unknown reason (n=2). Sixteen individuals (10 males and 6 females) agreed to participate. The mean age of the participants was 43.4 years (SD±7.7) and the duration of blindness was 14.4 years (SD±4.0).

Individuals under threat of becoming blind due to diabetes proliferative retinopathy (Paper I)
At a diabetes outpatient clinic (Uppsala), 26 individuals were identified as having proliferative retinopathy with an obvious risk of visual impairment. An experienced ophthalmologist using conventional clinical methods (fundus photography) diagnosed retinopathy. All these individuals were asked to participate in the interviews, and 21 (15 males and 6 females) consented. Their mean age was 45.1 years (SD±5.8) and they had had diabetes for an average of 32.6 years (SD±8.2).

Diabetic individuals responding to the Swedish Diabetes Empowerment Scale (Swe-DES-23) (Paper IV)
Individuals with diabetes type 1 and type 2 were recruited from two different settings. One was the medical centre’s diabetes clinic in Uppsala, and the other one was a primary health care centre in Dalarna. Individuals who visited these places during spring 2003 were asked to fill in the Swe-DES-23. Finally, the convenience sample consisted of 195 individuals. Twenty-five percent of them had type 1 diabetes, 25% had insulin-treated type 2 diabetes and 50% were individuals with type 2 diabetes not using insulin. Their mean age was 59.4 years (r=22-90 years) and duration of diabetes ranged from 1 to 52 years.
Blind diabetic individuals participating in the educational programme (Paper V)

The criteria for participation in the programme were: (a) age 20-65 years; (b) type 1 diabetes; (c) visual acuity ≤0.1. Individuals who fulfilled these criteria were sought through advertisements in tape-recorded newspapers, and through letters to the regional ophthalmologic centre, the medical centre’s diabetes clinic, and the primary health-care centres in a geographic area comprising 7000 square kilometres with 200,000 inhabitants. The search yielded 11 diabetic individuals (approximately 0.9% of all patients with type 1 diabetes in that area). Seven of these individuals agreed to participate in the study. An additional two individuals indicated an interest in participating and were also included in the study, even though they did not fully meet the criteria (one was 77 years old, and the other was found to be diagnosed with type 2 diabetes). The final sample consisted of 9 individuals (3 males/6 females, m=46 years, r=31-77 years). The mean duration of diabetes was 32.1 years (SD±17.6), and they had been blind for an average of 13.5 years (SD±8).

Reference group from the Swedish SWED-QUAL population studies (Papers I and II)

Data from two age- and gender-matched reference groups for self-perceived health were ordered from the Swedish SWED-QUAL population studies (Brorsson et al., 1993; 1996 (unpublished) for comparisons in Papers I and II. Two matched controls for each diabetic individual were selected randomly and 84 controls in Paper I and 78 controls in Paper II were available.

Measures

Diabetes- and blindness-related variables extracted from patient records

Information on the participants’ age, data on age at onset of diabetes, duration of diabetes, glycaemic control, and diabetic late complications other than retinopathy were collected from the hospital records. HbA1c had been assayed using ion exchange chromatographic method mono S (high performance liquid chromatography). The same method of analysis was used at the three different hospitals, with an upper normal limit of 5.3%. Microvascular complications were recorded; manifest albuminuria were repeatedly evaluated by means of Albustix strips. Neuropathy was registered as the presence of distinct subjective symptoms or physical findings (absent re-
flexes or sensory loss). Macro-vascular complications were defined as documented incidents of myocardial infarction or stroke.

Data on completed rehabilitative training and services were collected from the participants’ records at the ophthalmology centres.

Questionnaires

The questionnaires on self-perceived health, burden of diabetes, sense of coherence and empowerment used in Papers I-V are presented below.

Self-perceived health

Self-perceived health was measured using SWED-QUAL, a 63-item questionnaire adapted from the Medical Outcomes Study (Ware & Sherbourne, 1992) translated and tested for use in Swedish population by Brorson et al. (1993). The population study obtained reference values for self-perceived health. Brorsson and Ifver carried out a recent replication of the population study in 1996, which has not yet been published. The questionnaire measures different domains of health: physical functioning, satisfaction with physical health, role functioning (physical and emotional), pain, sleep, emotional well being (positive and negative feelings), family functioning (satisfaction with family life, marital, as well as sexual functioning) and general health perceptions. Items within a health domain are summed and linearly transformed into 0-100 scales such that a high score indicates better health. Cronbach’s alpha coefficient for the different domains varied from 0.62 to 0.96.

Self-perceived health was also measured using a single question EVGFP: “In general my health is Excellent-Very good-Good-Fair-Poor” (Paper IV).

Burden of diabetes

Burden of diabetes was measured using the SDD (Semantic Differential in Diabetes). This instrument was developed in 1990 (Wikblad et al., 1990) and has since been used as a clinical tool for assessing attitudes and burden of diabetes. The questionnaire used in the field of diabetes has possessed good reliability and validity (Wikblad et al., 1990). It contains seven-point semantic differentials with nine bipolar adjective pairs: constrained-free, weak-strong, dependent-independent, dominant-submissive, worthless-valuable, difficult-easy, unsafe-safe, tense-relaxed and monotonous-varied. The nine scales can be used either as single scales or be summed into a composed burden scale ranging from 1 (i.e. high burden) to 7 (i.e. low burden). The Cronbach’s alpha coefficient for the summed scale was 0.90.

Sense of Coherence

The Sense of Coherence scale (SOC), developed by Antonovsky (1993), measures overall ability to manage stressful situations. The scale contains 29 items, arranged on seven-point Likert scales with two anchoring responses,
giving the scale a range of scores from 29 to 203. An example of an item is: ‘Has it happened in the past that you were surprised by the behaviour of people whom you thought you knew well?’ The SOC questionnaire has proved to be psychometrically sound and reliable in several languages, including Swedish. Reliability, measured by Cronbach’s alpha coefficient, was 0.89.

**Empowerment**

In Paper IV reliability and validity of the Swedish version of the Diabetes Empowerment Scale (Swe-DES-23) were tested and in Paper V the tested instrument was used in evaluation of the educational programme. The Swe-DES-23 scale is a diabetes-specific empowerment questionnaire containing 23 items. Anderson et al (Anderson et al., 2000) developed the first version of the Diabetes Empowerment Scale (DES-37) at the University of Michigan Diabetes Research and Training Centre, USA and a diabetes psychologist translated the USA pilot version of DES-37 into Swedish. An authorized translator then performed a re-translation into US English. This Swedish pilot version was tested in a convenience sample of individuals with diabetes.

**Interviews**

**Individual interviews in Papers I-III**

An interview guide was used in Papers I-III. Areas of the individuals’ different dimensions of diabetes self-management, ability to influence and control their own situation and belief in the future were included. The interview guide consisted of five questions on self-perceived knowledge, skills and problems. The questions concerning self-perceived knowledge were formulated as follows:

Do you know…
- how insulin, food and physical activity interact?
- how to treat hypo/hyperglycaemia?

The question concerning skills was formulated as:
- can you give a concrete example of how you apply this knowledge into your self-management?

The questions regarding problems concerning insulin treatment and blood glucose levels were formulated as follows:

Do you experience any problems with:
- insulin treatment (e.g., painful injections or difficulty in finding an adequate injection site)?
- unstable blood glucose and hypoglycaemia?
In Paper II, the individuals’ ability to influence and control their own situation and their belief in the future was explored. The interview started with an open question: ‘What do you actually do to accurately manage your daily life?’ Probing questions were used in order to attain a complete picture. Belief in the future was explored with the following question: ‘What do you think about the future?’.

Increasing credibility includes activities that help the researcher negotiate with the study participants about the findings (Dahlgren et al., 2004). Therefore, after the analysis, the participants were asked in telephone interviews if they agreed with the interpretation of their answers. Three of the 39 respondents had recently died. Therefore, their responses were included in the analysis without confirmation. All the others (n=36) were reached by phone, and all but one agreed with the results of the qualitative analysis. The categorization of this participant’s answer was therefore slightly revised.

Focus-group interviews in Paper V

An interview guide was constructed to evaluate the participants’ opinions of the educational programme ‘I’m the Boss’ (Paper V). Open-ended questions were used to elicit a wide range of responses. The questions dealt with the educational method, opinions about the choice of topics, and their own as well as the facilitators’ qualifications. The focus group interviews were carried out directly after the programme was completed, and started with the question: “Do you think/feel that the educational programme met your expectations?”

Individual interviews - Evaluation of the effects of the educational programme (Paper V)

The interview guide for the individual interviews included questions on self-management problems, goal setting, diabetes and feelings, diabetes and stress, and social support. The interviews started with the question: “Why did you choose to participate in ‘I’m the boss’?” and continued with questions intended to encourage participants to illuminate their opinions about the different topics described above, e.g., ‘You told me that you have no good experience of social support - please tell me how you felt and whether you discussed it during the course.’

Intervention (Paper V)

An empowerment programme called ‘I’m the boss’ was implemented. (Wikblad et.al., 2004). The programme included six three-hour weekly sessions dealing with different aspects of living with diabetes as well as visual disability. Problem-based learning (PBL) was used as the educational
method. PBL is an eight-step process in which the participants are active learners and have to solve problems they themselves have formulated. The solutions to the problems may either be found in the literature, by asking experts, by having confidence in one's own reflection or in resources from others.

The process of PBL started with a take-off point being presented to the group members. These take-off points consisted of a tune or a recital text. These were produced in accordance with the planned curriculum/empowerment approach for the programme, which included (1) life satisfaction and goal setting; (2) problem solving; (3) coping with emotions, (4) coping with daily stress, (5) social support and (6) motivation. The group members then discussed their experiences and knowledge of the topic and applied existing knowledge and experience to the problem. They identified resources and discussed the learning issue (i.e., what information is needed to solve the problem). Tasks were distributed among the group members so that each of them knew what information he/she had to collect for the next session. At the next meeting, the new facts were presented so that all members could share the new knowledge. They also reflected upon their newly acquired knowledge and discussed how this new knowledge could be applied to their own daily self-management.

Procedure

Papers I-III

The interviews were conducted in the respondent’s home or place of work, or at the ophthalmic centres or diabetes outpatient clinics. During the interview, questionnaires for self-perceived health, SOC and SDD were completed, and questions on duration of blindness, duration of diabetes, education and current income were answered. The interviewer (JL) read out the questions and the response alternatives to the respondent, and filled in the questionnaire. Next, questions were posed concerning perceptions of diabetes self-management, ability to influence and control their own situation, as well as their belief in the future and completed rehabilitative training and services. Data on diabetes-related variables were collected from the patients’ hospital records after informed consent.

Paper IV

In Paper IV, individuals were asked to fill in Swe-DES-23 and complete the SDD and the single EVGFP scale. Written information and the questionnaires were sent by mail to the individuals who had agreed to participate and they were asked to mail the questionnaires to the authors within two weeks.
Diabetes-related data (duration of diabetes, treatment, presence of late complications and current HbA1c) were collected from the individuals’ medical records after their informed consent.

Paper V

Individuals presented in Paper V were asked to take part in an educational programme called ‘I am the Boss’. They were also asked if they agreed to complete the Swe-DES-23 questionnaire before and after the educational programme and answer interview questions related to ‘I’m the Boss’. These interviews were conducted as both focus group and individual interviews. The focus group interviews were conducted immediately after the last session, by one of the authors (JL). A registered nurse who did not participate in the educational programme interviewed each of the nine participants in their homes, six months after completion of the programme. The interviewer also read out the questions on Swe-DES-23 scale and the response alternatives, and filled in the questionnaire. The interviews lasted from 30 to 80 minutes and were tape-recorded and transcribed verbatim.

Data analysis

Statistical analysis

Stat View 5.0 was used for analysis in Papers I-III (SAS 1998). In Paper IV, analyses were performed using SPSS (Statistical Package for the Social Sciences). Results are presented as descriptive statistics (e.g., means±SD or median IQR). Parametric statistics were used in papers I-IV (Student’s t-test, ANOVA and confidence interval of 95%). In addition, the non-parametric Mann-Whitney U-test was employed in Paper I. Cronbach’s alpha was applied to test the reliability (homogeneity) of the questionnaires. In Papers I-III and V chi square tests (\(\chi^2\)) were used for comparisons of discontinuous data.

In paper I when testing differences between the groups regarding health-domains, the p-value was set to \(\leq 0.01\) as there may be a risk of the phenomenon mass significance. Bivariate analyses and correlation analyses (Student’s t-test and \(\chi^2\) test) were performed first to determine variables included in multiple logistic regression analysis. The variables included were age, financial status, emotional well-being (positive and negative feelings), role limitations due to emotional health, role limitations due to physical health, and general health perceptions. Multiple logistic regression analyses were used to determine variables contributing to an explanation of the variance in self-management. Independent variables were excluded in a stepwise procedure to find a significant model explaining the variance of self-management.
Before performing the statistical analyses ($\chi^2$) subgroups were constructed (Paper III). Individuals who scored excellent/very good/good health formed one subgroup (good health), and those who scored fair/poor formed another (poor health). Depending on the mean value for the SOC scale (144±23.8), the sample was divided into two subgroups: those who scored $\geq$144 points were categorized as having strong SOC, and those who scored <144 points were categorized as having weak SOC. Furthermore, strong SOC and power were combined into one subgroup as were weak SOC and non-power. Finally, SOC and non-power/weak SOC and power were put together in one subgroup.

In Paper IV, construct validity was assessed using exploratory factor analyses (principal components) to derive coherent and independent sub-scales from the 23 items included in the Swe-DES-23 scale. Inter-item correlations were identified using Pearson’s product-moment-correlation coefficient. Analysis of variance (ANOVA) and Student’s $t$-test were performed to elucidate discriminant validity.

Qualitative analysis.

In Papers I and II, self-reported knowledge regarding different aspects of diabetes self-management was categorized as present or absent. Individuals who expressed how they did apply their knowledge of self-management were labelled as having skills. Problems with insulin treatment, unstable blood glucose and hypoglycaemia were categorized as present or absent. Two of the authors (JL and KW) performed this analysis, discussed, and compared the results (agreement was 95%).

The qualitative data used in Paper II (e.g., ability to influence and control one’s own situation as well as belief in the future) were classified into two distinct categories (Miles & Huberman, 1994). According to the definition of ‘power’, developed by Barrett (1998), individuals who described themselves as independent, free to act intentionally and in control of the situation were categorized as powerful. Participants who felt they were not able to change, influence or control their own situation were regarded as powerless. Belief in the future was categorised as presence or absence.

The interviews in paper V were analysed using qualitative manifest and latent analysis (Graneheim & Lundman, 2004). The analysis of the interview text was performed in several steps by all authors in order to structure and categorize content. Findings were reported as theme, categories and sub-categories. The research team read the transcribed raw text several times to understand it as a whole and to perceive its essential characteristics.

Step 1. The analysis started with an organization of the text into two content areas: diabetes self-management and participants’ experiences of the educational programme. Afterwards, the text was read repeatedly to obtain a sense of the whole.
Step 2. The text was separated into meaning units, which were then condensed. The unit was reread line by line and labelled as codes. The coding was conducted independently, critically questioned and confirmed with the research team.

Step 3. The various codes were compared based on differences and similarities and were then sorted into seven sub-categories and two categories, which constituted the manifest content. Two of the authors (JL and KW) discussed the tentative categories. A process of reflection and discussion resulted in agreement on how to sort the codes.

Step 4. Finally, reflection on the categories based upon the researchers knowledge and experience provided phenomena that seemed to be relevant for integrating the categories into the theme (latent content analysis).

Ethical considerations

Taking part in the studies was voluntary, and the individuals were asked to participate. Individuals in all papers were given written information and individuals in Papers I-III and V were also informed verbally by telephone. Informed consent was obtained and the participants were made aware of their right to refuse to answer questions and of the fact that they could withdraw at any time. The medical ethics committees at the university hospitals in Uppsala and Örebro approved the study design (Papers I-III). The medical Ethics Committee at Uppsala University approved the design of the study in Papers IV and V. In Paper V, socio-demographic data are presented as group values and personal identifications were removed from the interview text to preserve confidentiality.
Results

Aspects of diabetes self-management and self-perceived health (Paper I)

Diabetic blind individuals and individuals with threat of blindness were compared regarding their diabetes self-management. Those who were blind had longer duration of diabetes, and their diabetes had occurred earlier in life. They were also afflicted with neuropathy to a higher degree (70% vs. 33%, $\chi^2=7.5$, df =1, p=0.0006). Characteristics of the two groups are presented in Table 2.

Table 2. Characteristics of diabetic individuals.

<table>
<thead>
<tr>
<th></th>
<th>Blind individuals (n=23)</th>
<th>Individuals with threat of blindness (n=21)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years) mean ± SD</td>
<td>47.4 ± 7.6</td>
<td>45.1 ± 5.8</td>
</tr>
<tr>
<td>Age at onset of diabetes (years) mean ± SD</td>
<td>8.7 ± 5.4*</td>
<td>12.3 ± 6.6</td>
</tr>
<tr>
<td>Diabetes duration (years) mean ± SD</td>
<td>38.7 ± 6.6*</td>
<td>32.8 ± 8.2</td>
</tr>
<tr>
<td>Glycaemic control (HbA1c %) mean ± SD</td>
<td>7.0 ± 0.8</td>
<td>7.8 ± 1.3</td>
</tr>
</tbody>
</table>

* Presence of late complications besides retinopathy:
  - Microvascular (neuropathy) (%) 70* 33
  - Macrovascular (%) 13 10

* p≤ 0.05

Self-management

Most of the blind individuals and those with threat of blindness expressed that they had knowledge about the interaction between insulin, food and exercise as well as how to manage hyperglycaemia and hypoglycaemia. De-
spite this awareness, particularly those who were blind reported having experienced problems with insulin treatment (21 vs. 6; $\chi^2=16.2$, df=1, $p=0.0001$), unstable blood glucose (17 vs. 3; $\chi^2=15.7$, df=1 $p=0.0001$) and hypoglycaemia (18 vs. 4; $\chi^2=15.4$, df=2, $p=0.0001$) in comparison with individuals threatened with blindness. Several of the blind diabetic individuals reported that they struggled with self-management problems and expressed this as follows, for example:

“The disease is more difficult to handle nowadays; I actually do not feel if my blood glucose is high or low. I just collapse, and because of that, I am dependent on others”.

“The insulin is much better today than it was 30 years ago, but I still think the disease is hard to understand. One of my biggest problems today is that I do not know if and when my blood glucose is low. My experience is that my blood glucose levels are much more unstable today even though I measure blood glucose regularly”.

Despite knowledge concerning self-management, the participants felt uncertain about how to apply this knowledge to solve their problems. Only 56% of the blind diabetic individuals could give concrete examples of how they applied knowledge about the interaction between insulin, food and exercise in their daily self-management.

Self-perceived health

Blind diabetic individuals’ perceived significantly lower self-perceived health than did those with threat of blindness in six of the 12 health domains, i.e. physical health, satisfaction with physical health, role limitations due to physical health, negative feelings, sleep and general health (Figure 1).

In addition, the blind diabetic individuals exhibited lower scores than did the age- and gender-matched reference group in the domains physical functioning, satisfaction with physical health and general health. In contrast, there were no significant differences in self-perceived health between diabetic individuals with threat of blindness and the age- and gender matched reference group (Figure 1).
Relation between self-management and self-perceived health

The logistic regression analysis showed that only one self-perceived health domain namely physical functioning due to role limitations, was significantly related to impaired self-management among the diabetic individuals (odds ratio OR 0.966). This means that for each point dropped in role limitations due to physical health, the risk for impaired self-management increases by 3.5% (coefficient=-.035; \(\chi^2=8.16\); df=1; p=0.004).

Self-perceived health and power (Paper II)

Self-perceived health

Blind diabetic individuals scored significantly lower than non-diabetic blind individuals in the health domains satisfaction with physical functioning posi-
tive feelings and general health. In comparison to the reference group, blind diabetic individuals scored significantly lower in physical functioning and general health. They were less satisfied with physical functioning and experienced more negative feelings, but scored significantly higher in role limitations due to emotional health.

The self-perceived health profile of the non-diabetic blind individuals showed a pattern similar to that of the age- and gender-matched reference group, with two exceptions. The non-diabetic blind individuals scored significantly higher than the reference group in positive feelings and lower in physical health (Figure 2).

![Figure 2. Differences in the health domains of self-perceived health between the reference group, scored as 0, blind diabetic individuals and blind non-diabetic individuals.](image)

**PF**= Physical functioning, **SPH**= Satisfaction with physical health, **RP**= Role limitations due to physical health, **BP**= Bodily Pain, **PE**= Positive emotion/feelings, **NE**= Negative emotion/feelings, **RE**= Role limitations due to emotional health, **SFL**= Satisfaction with family life, **MF**= Marital functioning, **SexF**= Sexual functioning, **GH**= General health

**Power**

The analysis of self-perceived health among blind diabetic individuals, as described above, depicts a pessimistic outcome. There are, however, individual differences. The concepts of powerful and powerless were used to
describe how blind individuals think and act in different day-to-day situations. One of the participants expressed the life situation as follows:

“I take care of the treatment myself. I do not take advice - I want to know the result to be able to control my own treatment…I want to be the boss in my own back yard.”

This quotation is one example of powerfulness. The participants described themselves as independent, free to act intentionally and in control of the situation. However, other participants expressed a feeling of dependence and had difficulty in achieving control over their own situation (powerlessness). One of the group members reflected:

“The combination of being blind and diabetic is boring…For example they don’t inform me about new aids at the ophthalmologic centre. …The health professionals are so mean and my whole situation is troublesome”.

Relation between self-perceived health and power
Blind individuals who experienced power were significantly more satisfied with their physical health, scored better emotional health (positive feelings and negative feelings) and perceived better general health compared to those categorized as powerless (Figure 3). Moreover, the experience of power was more common in the group of non-diabetic blind individuals (13 of 16) in comparison with the diabetic blind individuals (6 of 23) ($\chi^2$=9.44; df =1; p=0.001).
PF= Physical functioning, SPH= Satisfaction with physical health, RP= Role limitations due to physical health, BP= Bodily Pain, PE= Positive emotion/feelings, NE= Negative emotion/feels, RE= Role limitations due to emotional health, SFL= Satisfaction with family life, MF= Marital functioning, SexF= Sexual functioning, GH= General health

Figure 3. Self-perceived health profiles in blind individuals experiencing power and in those lacking power

Sense of coherence and power

Sense of coherence

The mean sense of coherence (SOC) score for the blind diabetic individuals was 138.3 (±22.4), for those with blindness for other reasons than diabetes the SOC score was 152.1 (±24.3) and for the two groups together 143.0 (±23.8). Table 3 illustrates the distribution of SOC in the groups of blind individuals. Participants with diabetes related blindness showed to a higher extent weak SOC compared to those with blindness for other reasons (n= 13 vs. 3; $\chi^2=4.2$; df=1; p=0.04).

More participants with strong SOC experienced better self-perceived health than those with weak SOC (n=18 vs. 3; $\chi^2=11.2$; df=1; p=0.0008).
Table 3. Number of blind diabetic and non-diabetic individuals with strong or weak SOC

<table>
<thead>
<tr>
<th>No of individuals with:</th>
<th>Blind diabetic individuals (n=23)</th>
<th>Blind non-diabetic individuals (n=16)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strong SOC</td>
<td>10</td>
<td>13</td>
</tr>
<tr>
<td>Weak SOC</td>
<td>13</td>
<td>3</td>
</tr>
</tbody>
</table>

Relations between sense of coherence and power

Fifteen blind individuals with strong SOC also experienced power and 12 individuals with weak SOC experienced non-power. The remaining 12 had combinations of high SOC and non-power/weak SOC and power. Distribution of the combinations of ‘SOC and power’ in blind diabetic individuals and in individuals who were blind for reasons other than diabetes are shown in Table 4.

Table 4. Distribution of the combinations of ‘SOC and power’ in blind diabetic individuals and individuals who are blind for reasons other than diabetes

<table>
<thead>
<tr>
<th>No of individuals with:</th>
<th>Blind diabetic individuals (n=23)</th>
<th>Blind non-diabetic individuals (n=16)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strong SOC and power</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Weak SOC and non-power</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Strong SOC and non-power/weak SOC and power</td>
<td>8</td>
<td>4</td>
</tr>
</tbody>
</table>

SOC and power in relation to self-perceived health, burden of diabetes, glycaemic control and diabetes self-management

Almost all individuals with the combination of strong SOC and power perceived good health (n=14 out of 15). Only 3 of those with weak SOC and non-power and 4 of those with the combinations of high SOC and non-power/weak SOC and power perceived good health ($\chi^2=17.7; \ df=2; p=0.0001$).

Burden of diabetes, as measured with SDD, was reported to be higher in blind diabetic individuals compared to diabetic individuals with threat of blindness (Table 5).

With regard to the individuals perceived burden of diabetes in relation to the various combinations of SOC and power, participants with the combination of strong SOC and power felt more valuable ($F=32.4; \ df=2/20; p=0.0001$), viewed their diabetes as easier to handle ($F=11.4; \ DF=2/20; p=0.0001$).
P=0.0006) and less dominant (F=6.7; df=2/20; p=0.003) compared with those having a combination of weak SOC and non-power as well as those with the combinations of strong SOC and non-power/weak SOC and power. In addition, those with high SOC and power had better glycaemic control than the two other groups (ns). Neither were there significant differences between the three groups of ‘power and SOC’ in experiences of self-management problems.

Table 5. **Mean values for SDD in blind diabetic individuals and diabetic individuals with threat of blindness**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Blind diabetic individuals (n=23)</th>
<th>Diabetic individuals with threat of blindness (n=21)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Free - constrained</td>
<td>3.4 ± 2.5</td>
<td>5.1 ± 2.4</td>
<td>0.03</td>
</tr>
<tr>
<td>Strong - weak</td>
<td>4.5 ± 2.0</td>
<td>6.1 ± 1.7</td>
<td>0.007</td>
</tr>
<tr>
<td>Relaxed - tensed</td>
<td>4.5 ± 2.1</td>
<td>6.1 ± 1.7</td>
<td>0.007</td>
</tr>
<tr>
<td>Safe - unsafe</td>
<td>4.2 ± 2.3</td>
<td>6.0 ± 1.7</td>
<td>0.006</td>
</tr>
<tr>
<td>Independent - dependent</td>
<td>5.1 ± 2.1</td>
<td>6.8 ± 0.4</td>
<td>0.0008</td>
</tr>
<tr>
<td>Valuable - worthless</td>
<td>4.3 ± 1.5</td>
<td>6.1 ± 1.9</td>
<td>0.0009</td>
</tr>
<tr>
<td>Submissive-dominant</td>
<td>4.3 ± 2.4</td>
<td>5.4 ± 2.4</td>
<td>0.1</td>
</tr>
<tr>
<td>Easy - difficult</td>
<td>3.3 ± 1.8</td>
<td>5.6 ± 2.0</td>
<td>0.0002</td>
</tr>
<tr>
<td>Varied - monotonous</td>
<td>4.6 ± 2.1</td>
<td>5.9 ± 2.1</td>
<td>0.05</td>
</tr>
</tbody>
</table>

(Lower score indicates higher burden of diabetes)

**Psychometric properties of the Swedish Diabetes Empowerment Scale (Swe-DES-23) (Paper IV)**

In paper IV the psychometric properties of the Swedish version of the Diabetes Empowerment Scale (Swe-DES-23) were determined. The results of confirmatory factor analysis provided evidence of convergent and discriminant validity for the four subscales underlying the Swe-DES-23:
• Goal achievement and overcoming barriers for goal achievement (10 items)
• Self-awareness (4 items)
• Managing stress (4 items)
• Assessing dissatisfaction and readiness to change (5 items)

The analysis showed that individuals with good self-reported health scored higher on all empowerment subscales with the exception of the subscale Assessing dissatisfaction and readiness to change. It was also found that individuals who scored low ‘burden of diabetes’ scored significantly higher on the empowerment subscales.

Only weak correlations were found between metabolic control and the empowerment subscales. The only correlation with presence of late complications was found for the Goal achievement and overcoming barriers for goal achievement subscale. The duration of diabetes showed weak correlation with the total DES, meaning that patients with short duration of illness scored higher on the total empowerment scale.

The Cronbach’s alpha coefficient for the total score was 0.91 and varied between 0.91 and 0.68 for the four subscales (internal consistency). Inter-item correlations were calculated to determine the unidimensionality of the scales. All inter-item correlations were significant at the p<0.0001 level, except for one double-loading item in Factor 4 (Assessing dissatisfaction and readiness to change) (p<0.03). The correlations in Factor 1 (Goal achievement and overcoming barriers to goal achievement) varied between 0.33 and 0.72 with a mean value of 0.51. The corresponding figures for Factors 2 (Self-awareness), 3 (Managing stress) and 4 (Assessing dissatisfaction and readiness to change) were: 0.50 (0.38-0.85), 0.51 (0.27-0.74) and 0.29 (0.16-0.53).

The conclusion was that Swe-DES-23 scale had acceptable validity and reliability. Thus, the scale could be a suitable tool in evaluating empowerment educational programmes.

Empowerment as an approach in diabetes self-management education (Paper V)

Evaluation of the educational programme using Swe-DES-23 showed that four of the nine participants increased their self-awareness and ability to manage stress and two individuals increased their goal achievement and readiness to change. The individuals’ differences in the total Swe-DES-23 scale varied between –0.6 and +1.4.

A qualitative analysis of the interviews explored whether and how the programme had inspired the participants to develop skills for managing daily
life. The analysis was summarised in a single theme: *An inspiring learning climate enhances self-efficacy*. This theme was formulated on the basis of two categories (*inspiring learning climate and self-efficacy*).

**Inspiring learning climate**

The participants expressed that the learning atmosphere was of utmost importance. A climate in which they could feel *safe, stimulated and creative* in finding solutions for self-management was important for learning.

The atmosphere in the group was described as very warm and the communication was reflective, secure and relaxed. One of the participants expressed this as follows:

“Next, time I visit my doctor I’ll dare to ask questions. It feels safe for me to speak.”

The participants considered the new knowledge to be stimulating, provided in a way that made sense to them.

“It’s important to talk with others in the same situation; it’s extremely useful and very very important. It gives me more than visiting the doctor twice a year, and getting the result from the HbA1c. During this education you get new ideas and …..yes time for each other.”

It was of great importance to the participants that they were allowed to influence the content of the programme and find a new way of learning. Coffee breaks allowed them to communicate and share experiences besides those related to diabetes. These aspects seemed to facilitate a creative atmosphere within the group.

**Self-efficacy**

Self-efficacy conceptualised in terms of the participants’ ability to *share knowledge* by *confirming* each other during the group sessions, added to their *self-confidence*.

The shared knowledge helped participants in their self-management and inspired them to apply this knowledge to solve everyday problems both directly and in the future:

“I change needles after every injection. Before I used the same needle 10 times.”

“I didn’t know before that a talking blood glucose meter existed, and maybe I’ll use it in the future.”
Participants confirmed each other during the group sessions, by listening to each other respectfully. They spoke about the feeling of ‘being somebody’, which one of the group members expressed in the following way:

“Well, now it’s confirmed that I’m the one who has the greatest knowledge about my own body. It’s not the doctor who should tell me what to do or how to do it.”

The participants experienced that they ‘were their own masters’ (self-confidence). One of the participants reflected upon the fact that her mother had always insisted on having control over her daughter’s blood glucose levels, which was irritating. She concluded:

“…now I have learned to say please let me do this myself, because this is my life. Nowadays, I feel much better”

The importance of seeking new knowledge by posing questions to the diabetes care team was stressed from the participants. One of the group members had problems with a painful shoulder. She read an article that gave her knowledge and inspired her to put questions to the diabetes team:

‘Nowadays I have the courage to ask my diabetes nurse about my aching shoulder.’

Participants gained the courage to reflect, discuss and revise the content of the group meetings. The educational programme also gave them ambitions and helped them to gain deeper insight into new possibilities.
Discussion

Diabetes Self-management

During the past decade, it seems that knowledge among diabetic individuals has improved. Wikblad (1991) found that one-third of the diabetic individuals in Uppsala had knowledge about interactions between food, insulin and physical activities and Smide (2000) stated that half of the diabetic individuals reported that they knew about this interaction. In the current study, approximately 80% of the participants expressed such knowledge of this as well as how to manage hypoglycaemia and hyperglycaemia. Improved diabetes knowledge might be explained as an effect of better diabetes educational programmes, an improved diabetes care organisation and nurses having received special diabetes education (Smide, 2000). In addition, the amount of factual material about diabetes on the Internet has increased.

Furthermore, even if many of the blind diabetic individuals in the current study reported that they had knowledge of diabetes self-management, only half (56%) of them could give one concrete example of how they applied that knowledge, which is surprising. One explanation is that they could not think of a good example because the disease is a matter of routine. Another possible explanation is defective diabetes self-management education.

The blind diabetic individuals reported more problems with unstable blood glucose and insulin treatment than did diabetic individuals with threat of blindness. Problems with unstable blood glucose can be difficult to handle due to many diverse factors, for example defective injection technique, alterations in food or exercise practice, lipohypertrophy (Johansson, 2000) development of late complications and long diabetes duration. Studies have reported a slow gastric emptying in patients with long diabetes duration (Horowitz et al., 2002) and/or late complications (Bryzer et al., 2002), probably caused by autonomic neuropathy which can lead to unstable blood glucose with hypoglycaemia and hyperglycaemia. Neuropathy, might lead to decreased sensitivity in the feet and hands. This might be an obstacle for physical activity as well as reading Braille with help of the fingertips, or for performing self-monitoring of blood glucose (SMBG) (Benbow et al., 1999; Benbow et al., 1998). Regular physical activity is an important cornerstone for stable blood glucose levels as well as self-monitoring of blood glucose is an important help in correcting blood glucose levels (Larsson et al., 1999).
Many diabetic individuals who have had diabetes for a long time display a complex clinical phenomenon called hypoglycaemia unawareness. Participants in the present study also expressed difficulty with unexpected hypoglycemia. Pedersen-Bjergaard and co-workers (2004) observed a similar pattern. As many patients in the clinical settings display unawareness, these researchers have proposed a standard classification system for this phenomenon.

Correction of fluctuating blood glucose levels can first be achieved when the diabetic individual and diabetes team have analysed the causes related to the fluctuating levels. It is not until the causes have been identified that various treatment alternatives can be introduced.

The blind diabetic individuals reported more problems with self-management than did diabetic individuals with threat of blindness. An explanation might be that the blind individuals were aware of self-management problems to a higher degree. They had experience and awareness of the seriousness of diabetes (e.g. becoming blind). This understanding may also influence other complications of diabetes, the improved awareness helping in detecting and solving self-management problems. Even though the blind diabetic individuals reported more problems with insulin treatment and blood glucose fluctuations, they had acceptable HbA1c levels (7.0%) compared with individuals with threat of blindness who did report less problems in this respect. These individuals showed a trend toward poorer glycaemic control (HbA1c level 7.8%). Similar results have also been described by Bernbaum et al. (1988b).

Self-perceived health

Previous studies have shown that individuals threatened with blindness scored poorer health and had more psychosocial problems (Bernbaum et al., 1988b; Bougeard et al., 2001; Wulsin et al., 1993) than did those with complete loss of vision. Individuals felt that their lives were in suspended animation and would continue to be so until their visual status became stable, through either recovery or becoming blind.

In contrast, the present study has shown that diabetic individuals with threat of becoming blind experienced good self-perceived health. This is easy to explain, in one way, because compared to the blind diabetic individuals they had fewer late complications, such as neuropathy, and their private economy was good. Neuropathy has been associated with low self-perceived health (Rubin & Peyrot, 1999; Wikblad et al., 1996). Furthermore, blind diabetic individuals in the current study had long duration of diabetes. It is known from other studies that long duration of diabetes, is commonly associated with poorer health (Klein et al., 2001; Wikblad et al., 1996).
Besides these diabetes-related factors, studies have emphasized the importance of socio-economic factors related to health. The blind diabetic individuals in the present study were well educated but low-income earners. They had been blind for many years and the blindness may have had impact on their opportunity to work and earn money. The fact that individuals with low income are more likely to experience poorer health has been verified in other studies (Glasgow et al., 1997; Rubin & Peyrot, 1999).

Surprisingly, the blind non-diabetic individuals perceived good health. This is an unexpected result, as many earlier studies have shown that this group scored low in health (Scott et al., 1999; Wang et al., 2000; Wilson et al., 1998). One explanation might be that the blind non-diabetic participants have successfully learned to cope with their handicap. A number of the participants in this study expressed an awareness of obtaining new values in life, for example simply being able to listen and enjoy birds singing every morning. This result is important, because many people in general and specifically those with diabetes are afraid of becoming blind. This result can perhaps provide courage to enable individuals ‘to see the light in the darkness’.

It is understandable that the group with diabetes-related blindness was less satisfied with their physical health and estimated their health as poor. These individuals live with multi-handicap: diabetes, blindness and other late complications such as neuropathy. They have to cope with both their blindness and a life-threatening illness, which includes worries about complications and complicated self-management. Peyrot (2003) used the word overwhelming when self-management makes great demands upon individuals and is perceived as burdensome and frustrating.

**Power and self-perceived health**

Blind individuals who expressed themselves as ‘powerful’ were more satisfied with their physical health, perceived more positive and fewer negative feelings, as well as better general health compared to those individuals who expressed themselves as ‘powerless’. A smaller amount of blind diabetic individuals expressed themselves as ‘powerful’ compared to those without diabetes. The blind individuals with diabetes struggled with the above-mentioned self-management problems that were considered time-consuming and complicated. This could be a barrier to managing/solving other everyday problems in a positive manner. Half of the blind diabetic individuals were found to have ‘power’. The reason why some blind diabetic individuals described themselves as ‘powerful’ and expressed a positive attitude to diabetes is not easy to explain. No correlation was found between power, attitude
and diabetes-related variables. Nor could any correlation between socio-demographic factors and power be found. Perhaps other variables that had not been measured had influenced their ability to achieve power. However, this could indicate that personality plays a positive role in managing daily life as a blind diabetic individual. In the interview, the individuals who described themselves as ‘powerful’ talked more about what they were able to manage rather than what they could not manage. One of the participants expressed this as follows:

“In my situation (e.g. the combination of blindness and diabetes) it is important to act creatively, for example nowadays I press the tooth paste directly into my mouth because that is the right place for it”.

Individuals with power have courage to act in a creative way and judge themselves as capable to handle different situations. On the other hand, individuals who describe themselves as less powerful might be afraid to make use of different strategies to manage their daily life.

If power is of importance for self-perceived health, it is necessary to focus on the individual’s resources and not only on the blindness and/or diabetes itself. For example, it is necessary to take part in the blind individual’s experience of their situation and ability to solve everyday problems (Upton & Bush, 1998). Taking part in detailed knowledge of different self-management strategies might give health professionals an increased awareness and knowledge in other care situations as well as in supporting other blind individuals.

Power and Sense of Coherence

The reason why the combination of power and strong SOC was more common among blind non-diabetic individuals than among those with diabetes-related blindness is not easy to explain. One possible explanation is that they have had weak power and SOC over the years. Another possible explanation is that the combination of blindness and diabetes is such a burden that the SOC is weakened. The cross-sectional design used in the present study did not provide such an explanation: to do so, a longitudinal design is necessary. Another explanation for these differences might be that blind diabetic individuals experienced a greater burden of diabetes self-management. This corresponds well to the individuals’ answers regarding the problems with self-management. Individuals who suffer from several conditions, such as a combination of blindness and diabetes, spend a considerable time engaged in everyday activity such as foot care, exercise, dietary considerations, self-monitoring of glucose, administration of multiple medications, and reading/listening to new knowledge. Management of these activities requires
constant planning to allow these individuals to have a simple life. This sometimes leads to limitations in their freedom and to a loss of independence.

Power and SOC in relation to burden of diabetes, glycaemic control and self-management

All participants with the combination of power and high SOC were more satisfied with their health, less burdened by their diabetes self-management and had better glycaemic control than were individuals with the combination of weak SOC and non-power. These results are in accordance with findings by Echols-Hurst (2000). Although the present study included blind individuals in contrast to the study on individuals with psychiatric diagnosis by Echols-Hurst, the result highlights the value of individuals’ strong SOC and power. Perhaps one way to improve power and/or SOC is to make the health professionals aware of how to support blind individuals move toward power and increase their sense of coherence. For example: Diabetes nurses can support blind diabetic individuals towards seeing a correspondence between their own hard work with daily living/self-management and any success being due to their own efforts and ability rather than to the interventions of professionals or luck. One way to support blind diabetic individuals ‘power and SOC’ is, perhaps to encourage them to meet other people in the same situation. Such an education must be built upon the diabetic individuals’ experiences and needs of knowledge and skills. This assumption is in line with the empowerment-based educational programme, which focused on supporting individuals in developing and enhancing their goal-setting, problem-solving and other psychosocial skills. The empowerment approach is now widely used in diabetes patient education programmes (Anderson et al., 1995; Bernbaum et al., 1988a; Bernbaum et al., 1989; Ellis et al., 2004; Via & Salyer, 1999). To measure the effects of empowerment programmes it is important to develop validated instruments (Day, 2000).

Empowerment scale and the evaluation of ‘I’m the boss’

A concern in comparing translated instruments is achieving linguistic and cultural equivalency (Beck et al., 2003). However, the semantic equivalence was acceptable as an authorized translator was used for the back translation. The conceptual equivalence has not been tested, but the intention has been to use the same theoretical empowerment construct as in the original US version (Anderson et al., 2000).

The results from testing the Swe-DES-23 were promising. However, the factor analysis showed a discrepancy between the US and Swedish versions,
in that the US version yielded three subscales and the Swedish version four subscales. However, the alpha values for the four subscales and the total SWE-DES-23 scale were acceptable. The difference was that the US subscale “Managing the Psychosocial Aspects of Diabetes” was divided into two subscales in the Swedish version: “Self-awareness” and “Managing stress”. The findings resulting in a discrepancy between the outcomes of factor analysis (e.g. subscales) in the different countries requires further investigation.

The hypotheses that were formulated to determine discriminant validity of Swe-DES-23 scale were in accordance with earlier research. Individuals who reported good health also had high scores on the Swe-DES-23. Other studies have found a significant association between good self-perceived health and high degree of empowerment (Rogers et al., 1997; Tiwari et al., 2005). Participants with low burden of diabetes had higher scores on the Swe-DES-23, which is in accordance with one other study (Gibson, 1995). No correlations were found between glycaemic control and the US DES-37 scale (Via & Salyer, 1999), nor did individuals with good metabolic control score higher on the Swe-DES-23. Diabetic individuals without late complications found it easier to overcome barriers to goal achievement than did those who had late complications. As presented in the current thesis in Paper I, it was found that diabetic individuals with late complications perceived problems with self-management. In light of this finding, it is easy to understand and explain why these individuals’ goal achievement is not easy to attain.

An overall conclusion is that the current Swe-DES-23 scale possesses acceptable validity and reliability. This confirms its utility in measuring empowerment-based education programmes, although the different subscales must be developed further and the questionnaire needs to be shortened for clinical use.

The evaluation of the educational empowerment programme, showed that some of the participants improved their diabetes empowerment in the subscales ‘self-awareness’ and ‘ability to manage stress’.

An analysis of the qualitative interviews showed that they corresponded well with the quantitative data. An interpretation is that the cornerstone of self-efficacy is built upon the concepts of self-confidence, knowledge and confirmation. Self-confidence is a mode, which allows individuals to have positive yet realistic views of themselves and their situation. The participants shared knowledge and experiences and reflected upon different situations, problems and solutions related to diabetes self-management as well as to their respective life situations. This result is in accordance with findings of another author Sigurdardottir (2005) who stated that, for individuals with diabetes, two key concepts in achieving self-efficacy are reflection and understanding.

When the group members confirmed and accepted each other, this led to a solid foundation for good feelings about themselves and their self-
confidence. Perhaps, this social support is of utmost importance for blind diabetic individuals in increasing their self-efficacy. Aside from that, they might feel shame for having becoming blind. One of the reasons for them becoming blind is, perhaps, that they had high blood glucose levels for a number of years. In such a situation, it is easy to reproach oneself for neglecting self-management. It is, therefore, essential to get support from others in the same situation, which leads to a feeling of pride, self-confidence and self-efficacy. Glasgow et al., (1999) found that weak as well as strong social support might be a barrier to achieving self-efficacy.

An empowerment group education programme using problem-based learning has advantages for blind diabetic individuals. It seems that the learning climate in its safety stimulated and creatively inspired the group members’ self-efficacy. The analysis of the interview results was formulated into the theme ‘An inspiring learning climate enhances self-efficacy/empowerment’.

Individuals with diabetes have different kinds of obstacles concerning the disease, the treatment and self-management. It is therefore impossible to offer one kind of educational programme that is suitable for all diabetic individuals; individually tailored patient educational programmes are essential.

Methodological considerations
Sample
The primary limitation of this study concerns the sample size in Papers I-III and V. A larger size may have given another picture. Furthermore, few diabetic individuals today become blind and the population is therefore limited. The sample in Papers I-III was collected with help from three adjacent ophthalmic outpatient clinics Dalarna, Uppsala- and Örebro areas. Respondents were asked if they had previously participated in a rehabilitation programme. A majority of the individuals had participated in rehabilitation programmes several years earlier. This, and the fact that few differences in the rehabilitation programmes emerged between the Dalarna, Uppsala and Örebro areas suggest that this had not affected the results to any appreciable extent (Paper I). The sample in Paper V was obtained through a complete screening of individuals with blindness caused by diabetes living in a defined geographical area, which is a strength in that aspect.

Instruments
The instruments SWED-QUAL, SOC, and SDD are well-known instruments with proven validity and reliability. SWED-QUAL is a generic self-perceived health questionnaire that enabled a comparison between blind
diabetic individuals, those with threat of becoming blind, and a Swedish reference-group. A limitation is that Paper I did not include diabetes-specific questions concerning self-perceived health. For this reason, we might lack the sensitivity to detect differences between blind diabetic individuals and those with threat of becoming blind that has arisen due to diabetes. On the other hand, we did in fact ask the individuals if they had experienced any problems with diabetes self-management. Thus, their diabetes-related problems were included in the results.

The Swe-DES-23 had acceptable validity and reliability (Paper IV). This confirms its utility, although the different subscales must be further developed. Thorncroft & Slade (2000) has identified three dimensions of feasibility regarding psychometric properties of measures, namely applicability, acceptability and practicality. The applicability of a measure is the degree of its importance to users. Few empowerment measures are available in Sweden in diabetes care, despite a growing interest in empowerment educational programmes (applicability). The participants who fulfilled the Swe-DES-23 declared that the questionnaire was easy to understand and answer (acceptability). There is a manual available for Swe-DES-23, describing in detail how to score and interpret the data, but the questionnaire must be shortened for clinical use (practicality).

Interviews

The interviews in paper I-III were conducted in a place where the respondents could feel safe and calm. The individual interviews in Paper V were conducted by a trained nurse in the respondent’s home. It was of great importance, especially for the blind individuals, that they were in a place they recognised and felt safe. The interviewer experienced interviewing blind individuals as a new and difficult experience. Not having eye contact was difficult in the beginning. Therefore, the interviewer asked more questions to confirm the participants’ answers, e.g., ‘You told me that you experience that your health is excellent, is that right?’ During the interviews, the interviewer’s experience with the interview technique grew and the interviews became easier to perform.

Validity – truth value

In Paper I the diabetic individuals with the threat of becoming blind responded positively on the questionnaires SWED-QUAL, SOC and SDD. There is a risk of ‘response bias’, which is the tendency of some respondents to improve their responses. According to Polit and Beck (2003) this problem is very difficult to control. They suggested that the creation of a permissive atmosphere and provisions for respondent confidentiality encourage openness. The impression during these interviews was that the respondents an-
answered the questions honestly. The questionnaires were completed during the interviews.

In Paper II, after completing the analysis, the participants were asked in a telephone interview if they agreed with the interpretation of their answers. This increased the credibility of the study, according to Dahlgren et al (2004).

The interviews in Paper V were complementary to the Swe-DES-23 questionnaire regarding the effects of the educational programme ‘I’m the Boss’. The two different methods, qualitative interviews (focus as well as individual interviews) and the questionnaire partially supported each other. The use of multiple methods allows researchers to counterbalance the methods’ respective strengths and weaknesses. Therefore, through the use of multiple data collection methods, the credibility of the results might increase (Polit & Beck, 2003). The individuals completed the Swe-DES-23 immediately prior to the start of the educational programme and six months after they had completed the educational programme. The repeated measure probably did not affect the result, since the individual would not have been able to remember their answers to the first interview after such a long period.

One limitation of the intervention (Paper V) might be that we included one individual who was older than the other group members were and one with type 2 diabetes. Some of the other participants stated that they would have preferred a more homogenous age distribution that would have facilitated their ability to understand all group members’ social life situations. However, we do not feel that this influenced the intervention in a negative way.

Strength of the intervention (Paper V) was that six months after the educational programme was completed, the participants were asked if something had happened in their lives, such as negative or positive events. The external events that might take place can affect the outcome of the intervention positively or negatively. One of the participants had had a stroke after completing the educational programme, but was still lucid and positive about the educational programme. The other participants reported no events.

Finally, a randomised controlled design would have strengthened the results of the intervention study. The sample of blind diabetic individuals is though small for implementing such a design.
Conclusions

- Earlier studies have shown that diabetic individuals with threat of becoming blind experience poorer health than those who already have gone blind. That could not be verified. Blind diabetic individuals had significantly poorer health compared to those with proliferative retinopathy and an obvious risk of blindness.

- Blind diabetic individuals experience problems in their daily self-management of the disease. Role limitations due to physical health seemed to be associated with self-management problems. Therefore, these individuals need specific support to cope well with the problems caused by diabetes and blindness.

- The experience of power is important for the perception of health. It is possible to identify individuals lacking power. These people can be expected to benefit from participation in empowerment group education.

- The combination of power and strong sense of coherence seems fruitful. Individuals experiencing both power and strong sense of coherence perceived better health, experienced less burden of diabetes and had better glycaemic control than those with the combination of weak sense of coherence and non-power. Supporting patients’ power should thus be an important issue in diabetes care.

- The Diabetes Empowerment Scale in its Swedish version (Swe-DES-23) has been shown to be reliable concerning internal consistency and has achieved the necessary level of equivalence. The results indicate that Swe-DES-23 may be useful in evaluating empowerment patient education programmes.

- Participants in the empowerment education programme increased their self-efficacy and diabetes knowledge. Empowerment programmes may enhance power and health.

Clinical implications

The outcomes of the current studies have shown that blind diabetic individuals need support in managing diabetes treatment and care in order to preserve good health. Hence, it is important that the diabetes care team continuously encourages this vulnerable group for example by arranging regular empowerment group education meetings.
Further research

The findings in this thesis are based on small samples. It is therefore desirable to further study the importance of power and empowerment in randomized controlled studies with larger samples. Since the group of blind diabetic individuals is relatively small in Sweden the coming studies ought to be expanded to include blind diabetic individuals in several European countries.
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