Powerful together with diabetes

The development and evaluation of a social network based intervention for Dutch, Surinamese, Turkish and Moroccan people with type 2 diabetes living in socioeconomically deprived neighbourhoods

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In the last 30 years, the number of people with type 2 diabetes has more than doubled globally. People living in socioeconomically deprived neighbourhoods are disproportionally affected by this condition and also have more diabetes related complications.

Complying with and maintaining the complex health regimen needed for diabetes also known as diabetes self-management, is challenging for socioeconomically deprived patients. The social networks of patients play an important role in diabetes self-management. Relatives and friends can facilitate or hinder diabetes self-management by providing social support or social influences such as peer pressure, social norms and role models.

Powerful Together with Diabetes is a newly developed intervention with a focus on the social networks of patients living in socioeconomically deprived neighbourhoods. It aimed to improve glycemic control by increasing social support and diminishing hindering social influences on diabetes self-management. This thesis describes the development and evaluation of the process and effects of this intervention.

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POWERFUL TOGETHER WITH DIABETES

The development and evaluation of a social network based intervention for Dutch, Surinamese, Turkish and Moroccan people with type 2 diabetes living in socioeconomically deprived neighbourhoods

Charlotte Vissenberg
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POWERFUL TOGETHER WITH DIABETES

The development and evaluation of a social network based intervention for Dutch, Surinamese, Turkish and Moroccan people with type 2 diabetes living in socioeconomically deprived neighbourhoods

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General Introduction
GENERAL INTRODUCTION

This thesis describes the development and evaluation of the social network based intervention Powerful Together with Diabetes targeted at Dutch, Turkish, Moroccan and Surinamese patients with type 2 diabetes (T2D) living in socioeconomically deprived neighbourhoods. This intervention aims to increase social support for diabetes self-management and to decrease social influences hindering diabetes self-management (e.g. peer pressure and social norms). This chapter describes type 2 diabetes and its prevalence, diabetes self-management and usual diabetes care in the Netherlands, the target population of this thesis (socioeconomically deprived patients) and concludes with the objectives and outline of this thesis.

Type 2 diabetes

T2D is a chronic condition that has a major impact on quality of life. People with T2D have too much glucose in their blood which causes health problems. Normally the cells in the pancreas produce the right amount of insulin to process the amount of glucose in the blood. In people with T2D, this balance is distorted because the pancreas produces little or no insulin or because the body cells do not optimally respond to insulin anymore.

Having T2D has a negative impact on both quality of life in general and on health related quality of life. It is associated with microvascular complications like nephropathy, retinopathy and neuropathy. Besides this, in these patients the risk of cardiovascular disease is more than doubled and their life expectancy is diminished. Diabetes related complications can be prevented or postponed by preventing hyperglycemia which reduces microvascular complications, and macrovascular complications by the reduction of the well-known cardiovascular risk factors (e.g. smoking, hypertension and dyslipidemia) and the improvement of weight and lifestyle factors such as overeating and physical inactivity.

Prevalence of type 2 diabetes

In the last 30 years, the number of people with T2D has more than doubled globally which is related to an increase in the prevalence of obesity worldwide. Where T2D was first typically found in adults, now this disease is also observed in children and adolescents. In 2014, 1,078,400 people were registered by their general practitioner to have diabetes (66,1 for every 1,000 men and 61,8 for every 1,000 women). Of these people, 90% has T2D.
The prevalence of T2D is higher among people with a lower educational background. In the Netherlands, in 2012, 13.7% of the people that completed primary school only had T2D compared to 2.7% of the people that completed higher education or university. Also ethnic minority populations living in high income countries show an increased risk, e.g. among people originally coming from Turkey, Morocco and Suriname in the Netherlands, the prevalence of T2D is 2-3 times higher than that of the original Dutch population. These differences can only be partly explained by their lower socioeconomic status and higher prevalence of obesity. Other factors such as genetic susceptibility, lifestyle (e.g. physical inactivity high caloric intake) and environmental factors (e.g. stress) might account for this increased prevalence as well.

People in lower socioeconomic groups are not only disproportionately affected by T2D, they also have more diabetes-related complications and higher diabetes-related mortality compared to people in higher socioeconomic groups. In Europe, having a lower socioeconomic position is related to higher rates of mortality from diabetes with a described relative risk of dying from diabetes of 3.4 (95% CI 2.6–4.6) for women and 2.0 (95% CI 1.7–2.4) for men with disadvantaged socioeconomic positions.

Ethnic minority populations with T2D in the Netherlands also have an increased mortality and more diabetes related complications. In Surinamese Hindustani the (age-adjusted) relative risk for end-stage renal failure due to diabetes is increased 22 times. Further, the prevalence of microvascular complications such as retinopathy and microalbuminuria and macrovascular complications such as heart disease was higher in South Asians with an (age and sex adjusted) odds ratio for microalbuminuria of 1.78 in South Asians versus Europeans. Finally, cardiovascular risk factors are more prevalent in Turkish and Moroccan patients than in Dutch patients and South Asians have a higher prevalence of hypertension than other Europeans.

**Diabetes self-management and usual diabetes care in the Netherlands**
People with T2D are asked to be responsible for the daily management of their disease by performing self-care activities, also known as diabetes self-management (DSM). DSM encompasses active participation by someone in his or her own health care decisions and interventions. In practice in T2D this means an adequate use of medications, if applicable self-monitoring of blood glucose, eating healthy and being physically active, regularly checking and taking adequate care of the feet and dealing adequately with diabetes in every situation.
This means that people with diabetes have to master a complex health regimen that might change over time because of the progressive nature of this disease. This requires, besides treatment intensification, also ongoing diabetes self-management education. According to the American Association of Diabetes Educators and the American Diabetes Association “Diabetes self-management education (DSME) is the ongoing process of facilitating the knowledge, skill, and ability necessary for diabetes self-care. This process incorporates the needs, goals, and life experiences of the person with diabetes and is guided by evidence-based standards.”

According to the Dutch guideline for general practitioners regarding T2D, diabetes care starts with diabetes self-management education (DSME). The aims of this DSME are to provide patients with insights in the importance of:

- Targets for glycemic parameters, lipids and blood pressure
- A healthy lifestyle (to quit smoking, to exercise for at least 30 minutes, or in case of overweight 60 minutes a day, in overweight or obese patients to lose 5-10% of their weight, and to eat healthy: less saturated fat, more fibers, little alcohol)
- Formulating achievable goals with regard to weight, smoking, physical activity and medication adherence
- Daily checking of the feet and wearing appropriate shoes and socks
- Regular control visits
- Recognizing and dealing with hyper and hypoglycemia
- Dealing adequately with illness, fever, vomiting and travelling
- Controlling and regulating blood glucose levels (if appropriate)

For nutritional advice and guidance patients should be referred to a dietician. If education, adjustments in nutrition and stimulating physical activity do not result in reaching the right blood glucose levels, the GP will start with oral medications. If these do not have the desired effects the levels of these medications will be adjusted or an insulin treatment will be started. When an insulin treatment is started patients are redirected to a diabetes nurse who will educate the patient about hypoglycemia, the self-monitoring of blood glucose, and adjusting insulin dosages if necessary. The diabetes nurse also adjusts insulin dosages and performs periodically checkups.

**Diabetes self-management in socioeconomically deprived groups**

The disproportionate prevalence of diabetes related complications among socioeconomically deprived people with T2D is partly accounted for by a poorer glycemic control, related to less adequate self-management behaviours. Complying with and maintaining the complex health regimen needed for diabetes seems to be challenging, especially for socioeconomically deprived patients. Low incomes,
a low educational level and living in a deprived neighbourhood are associated with a lower prevalence of blood glucose monitoring and not knowing how to deal with extreme blood glucose levels. Further, especially the combination of smoking, physical inactivity and a lower consumption of fruit and vegetables is prevalent in socioeconomically deprived groups in the Netherlands, including ethnic minority groups.

There are multiple factors that influence self-management behaviours among socioeconomically deprived patients, including ethnic minorities, such as a lack of knowledge, low health literacy, low risk perception, low outcome expectations, low self-efficacy and specific socioeconomic barriers (lack of financial resources, environmental factors).

Also social interactions with friends and family members have a major impact on DSM. Social support, the aid and assistance exchanged through social relationships and interpersonal transactions, has a positive influence on DSM. However, an increasing amount of studies shows that significant others can also hinder DSM by interfering with or paying too much attention to DSM.

Socioeconomically deprived patients seem to have less access to supportive social networks and seem to have less sources of social support in their social environments. They also receive less social support that is needed for adherence to the regimen of a chronic condition such as diabetes. In addition, these patients are often confronted with strong social influences from their immediate social environments that hinder DSM such as peer pressure, specific cultural beliefs and expectations and fewer positive role models which might not be helpful for DSM.

There is a need for well described effective interventions in socioeconomically deprived groups that support patients with T2D in their DSM. Reviews show that there are interventions that seem promising but they mainly report on short term effects and it remains unclear if the intended population participated. Also, it remains unclear what makes interventions in socioeconomically deprived groups effective. We hypothesized that not only social support but other social influences as well should be intervened on in this target population to improve and especially maintain self-management behaviors.

More specifically, we hypothesized that involving the patient’s social network is an important condition to be able to increase knowledge, skills and risk perception to improve DSM and to create the conditions needed for behaviour maintenance.
Therefore, though we do pay attention to these determinants during the intervention, strengthening and expanding the social networks of socioeconomically deprived patients with diabetes related resources was chosen as the primary focus of the intervention we developed during this project. To our knowledge there are no interventions that focus simultaneously on social support and hindering social influences in this target population.

**Objectives**

The aim of this project was to develop a theory and evidence based intervention with a focus on the social networks of patients targeted at Dutch, Turkish, Moroccan and Surinamese patients with T2D living in socioeconomically deprived neighbourhoods with suboptimal glycemic control (HbA1c > 53 mmol/mol). The aim of the intervention was to improve glycemic control by increasing social support and diminishing hindering social influences on DSM.

The *Powerful Together with Diabetes* intervention was evaluated in a quasi-experimental study with a control group that received a standard group based educational intervention and a second control group that received usual care. We aimed to evaluate the effects of the intervention (*Powerful Together with Diabetes*) on haemoglobin A1C (HbA1c), quality of life, health-related outcome measures, DSM, and intermediate outcome measures compared with the intervention for the comparison group (*Know Your Sugar*) and standard care at 3, 10, and 16 months. Further, we aimed to assess the feasibility and cost effectiveness of the intervention.

We evaluated the intervention both qualitatively and quantitatively through a questionnaire, in depth semi-structured interviews and by the collection of biomedical outcome measures from the participants’ medical files. The design is described in more detail in chapter 3.

**Outline**

In chapter 2 we explore the social networks of socioeconomically deprived patients and its relationships with self-management behaviours followed by a description of the intervention development according to Intervention Mapping. Chapter 3 describes the study protocol used to evaluate the intervention. Chapter 4 describes the changes in social support and social influences following the intervention and important intervention strategies responsible for these changes. Chapter 5 describes the effects of the intervention on self-management behaviours and chapter 6 describes factors affecting the recruitment and retention of socioeconomically deprived patients in the intervention. In the general discussion, chapter 7, the im-
Applications of this thesis for health promotion and research in socioeconomically deprived patients are discussed.
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Development of the social network-based intervention ‘Powerful Together with Diabetes’ using Intervention Mapping

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INTRODUCTION

*Powerful Together with Diabetes* was developed according to the Intervention Mapping (IM) method. IM is a framework for the development of theory and evidence-informed health promotion interventions to enable health educators to create interventions that are feasible and have a high likelihood of being effective. The IM framework provides guidelines and tools for: i) the empirical and theoretical foundations of health promotion programmes, ii) the application of theory, iii) the translation of theory into actual programmes and materials, and iv) the management of programme adoption, implementation and evaluation.²

This chapter describes the development of the intervention *Powerful Together with Diabetes* based on the first four phases of IM (box 1): 1) Conducting a needs assessment, 2) Creating performance and change objectives, 3) Selecting theory-based intervention methods and practical strategies, and 4) Translating methods and strategies into an appropriately organised programme.

Because a description of the development of the entire intervention is beyond the scope of this chapter, development of only the most distinctive features of this intervention is outlined here. This involves a specific focus on social support and social influences that affect self-management, particularly in patients from socioeconomically disadvantaged neighbourhoods, and on examining the specific educational requirements of patients living in such neighbourhoods.
Chapter 2

**BOX 1 | Consecutive steps in Intervention Mapping (IM): this research focuses on the first four phases only.**

**IM 1: Conduct a needs assessment**
Assessment of the health problem, its related behaviour and environmental conditions, and associated determinants for the at-risk population. This phase resulted in a risk model of factors underlying diabetes self-management of diabetic patients living in socioeconomically deprived neighbourhoods.

**IM 2: Create matrices of change objectives based on the determinants of behaviour and environmental conditions**
The matrices of change objectives provide the basis for the intervention by specifying who and what will change as a result of the intervention. This phase resulted in matrices of different ecological levels (e.g. individual, interpersonal and group) that combine performance objectives for diabetic patients, their significant others and their intervention group, with selected personal and external determinants to produce change objectives, i.e. the most immediate target of the intervention.

**IM 3: Select theory-based intervention methods and practical strategies**
Selection of theory-informed intervention methods and practical intervention strategies to address the identified determinants. This phase resulted in an overview of useful and applicable methods/strategies for diabetic patients in lower socioeconomic groups, to address the identified determinants.

**IM 4: Translate methods and strategies into an organised programme**
Design and organisation of the programme by translating theoretical methods and strategies into programme components and materials. This phase also includes pretesting and pilot testing of programme components and strategies with intended implementers and recipients. The result is the intervention *Powerful Together with Diabetes*, its programme materials and protocols.

**IM 5: Plan for adoption, implementation and sustainability of the programme**
Specification of adoption and implementation plans and planning programme adoption and implementation. This phase results in matrices with performance and change objectives for determinants related to programme adoption and implementation among participants and group leaders. Appropriate methods and strategies to address these determinants are presented.

**IM 6: Generate an evaluation plan**
This phase involves the planning of outcome and process evaluations to assess the intervention effects on quality of life and intermediate determinants (see logic model, fig. 2). This phase results in an evaluation design.

1. **CONDUCTING A NEEDS ASSESSMENT**

The grant proposal for this study stipulated an intervention that was aimed at improving diabetes self-management through the provision of social support among Dutch, Moroccan, Turkish, Surinamese (box 2) patients from socioeconomically deprived neighbourhoods with suboptimal glycaemic control (HbA1c > 7% or 53 mmol/mol). Therefore, our needs assessment focused on determinants associated with self-management behaviours, with special attention for the role of social support among this target population.
In 2016, the Netherlands had 16.9 million inhabitants. Of these, one in five inhabitants belongs to a migrant population. About half of the migrant populations (55.9%) migrated from non-Western countries. In 2010, two thirds of these migrant populations belonged to the four largest migrant populations in the Netherlands; the largest group was from Turkish descent, followed by Moroccan and Surinamese groups. The Surinamese group consists of people with different ethnic backgrounds, i.e. Hindustani, Creole, Javanese, Chinese and Marron. In the Netherlands, the Hindustani and the Creole form the largest groups. The term ‘Hindustani Surinamese’ is used to refer to people of South Asian ancestral origin who migrated to the Netherlands via Suriname. The term ‘Creole Surinamese’ is used to refer to people who are descended from the slaves that were transported to Suriname from Africa.

**BOX 2 | Migrant populations in the Netherlands**

**1.1 Methods**
The needs assessment consisted of a literature review and a qualitative study.

**1.1.1 Literature review**
The needs assessment started with a scoping review of the literature (unpublished) on social support and an exploration of theories related to self-management: the theory of self-regulation, different self-management theories, and the transactional model of stress and coping, relapse prevention, and social learning theories. The databases PubMed, Embase, PsycINFO and Google Scholar were searched for articles describing the influence of social support on diabetes outcomes and diabetes self-management. A search was also made for intervention studies that aimed to increase or create social support for diabetes self-management.

The literature review provided a general overview of the most important factors related to self-management of people with type 2 diabetes, i.e. low outcome expectations, low self-efficacy, lack of knowledge on diabetes, and low risk perception. The review also revealed that not only social support, but also other social influences in the immediate social environments of the patients (e.g. peer pressure, social norms, and role models) are important for self-management, especially in patients from socioeconomically deprived neighbourhoods.

However, information was lacking on the precise nature of these determinants among our target population. For example, which social norms and role models are present in the social environment of these patients and how do these affect self-management behaviours? What form does peer pressure take and how is this related to self-management behaviours? How can these determinants be influenced? With the aim to address these questions, we then conducted a qualitative study to
further examine the relation between social support and other social determinants on self-management behaviours. This qualitative study was conducted among people with type 2 diabetes from socioeconomically deprived neighbourhoods, particularly Turkish, Moroccan, Surinamese and Dutch patients.

1.1.2 Qualitative study
The qualitative study consisted of semi-structured in-depth interviews with healthcare professionals and their patients. In addition, participant observations took place and we analysed a forum held for people with diabetes. Finally, we also re-analysed the in-depth interviews and focus group discussions with people with diabetes that were organised and conducted by fellow researchers.

Interviews
Semi-structured in-depth interviews were held with people with diabetes from lower socioeconomic groups (n=21) and their healthcare professionals (n=3). They were recruited via a diabetes nurse who was working in a socioeconomically deprived neighbourhood and via an advertisement placed on a diabetes forum. All three healthcare professionals (two diabetes nurses and one general practice assistant) worked in socioeconomically deprived neighbourhoods and were recruited with the help of general practitioners (GPs) involved in the present study.

The 21 patient interviews were conducted at the respondents’ homes or, if preferred, at a local community centre or healthcare centre (each interview lasted 60-90 min). For all interviews, a topic list was used which was revised in the light of emerging findings. Relevant topics (addendum 1) included: self-management in daily life, barriers and facilitators to self-management, interactions with healthcare professionals, and the role of relatives/friends in self-management.

After patients had provided informed consent, the interviews were recorded, transcribed verbatim and analysed with MAXQDA software using framework analyses. In addition, a secondary analysis was performed on data from previous research (interviews and focus group discussions with people with diabetes from socioeconomically deprived neighbourhoods). These interviews were held with Surinamese, Turkish and Moroccan patients, as well as with patients from lower socioeconomic groups in general, and included topics similar to those used in our own interviews. Parts of these interviews were already coded in MAXQDA which enabled us to incorporate the relevant codes into our own analyses; the remaining interviews were analysed using framework analyses.
Observations
The daily practice of a diabetes nurse working in a socioeconomically deprived neighbourhood in The Hague was closely observed. Observations were also made during a 6-week intervention called ‘Dealing with Diabetes’ that was organised for Turkish, Moroccan and Dutch people with type 2 diabetes in socioeconomically deprived neighbourhoods in Amsterdam. This took place by means of a participant, non-structured observation. One of our research group (C.V.) observed all patient consultations with the diabetes nurse for two days from 8.00-17.00 hours. The diabetes nurse saw (on average) 20 patients per day. The researcher sat in the nurse’s office (unobtrusively at the back) and was introduced to each patient as a colleague who would observe the consultations. All patients were asked if they had any questions regarding this observation; moreover, each patient was guaranteed his/her anonymity and was asked to provide informed consent. None of the patients had any questions and none refused participation. During this group-based intervention, the researcher (C.V.) sat at the back of the room whilst the patients took part in the intervention.

During the observations, the researcher (C.V.) wrote down everything that she saw and heard. After each consultation, she checked her findings with the diabetes nurse and the health promotor to ensure/optimise validity. These field notes were subsequently analysed using thematic charting.

Analysis of forums for people with diabetes
Finally, we analysed all the public content of forums held for people with diabetes (from April 2009 to April 2010). It appears that individuals (subjectively) report worse health and more often seek health information online, than individuals that (subjectively) report good health. Further, much information sought online is related to ‘sensitive’ health topics that people prefer not to discuss with others \(^\text{18}\). Kummervold et al. found that almost half of their respondents discussed personal problems online that they did not discuss with other people \(^\text{19}\). Therefore, we analysed all the public content of a forum organised for people with diabetes \(^\text{20}\).

Although this forum was not specifically intended for patients from socioeconomically deprived neighbourhoods, we hypothesised that these groups would participate due to the above-mentioned factors, which was also in accordance with our needs assessment so far. Particular attention was paid to comments that indicated a lower socioeconomic background, e.g. related to educational level or profession, and to writing that included language that we recognised from our needs assessment phase.
We analysed all public content from this forum from April 2009 to April 2010. The content was analysed using selective coding, focusing only on barriers/facilitators to self-management and the role of significant others (e.g. relatives and friends) in the performance of self-management. Additional analyses were performed using framework analysis.12

1.3 Results
According to the Intervention Mapping method, the results of the needs assessment are summarised in a logic model (figure 1). This model is based on the results of the literature review and the qualitative study and outlines: i) the personal and external determinants related to the self-management behaviours of the target population, and ii) also that of people in their immediate social environment. This section describes the development of the logic model.

**Development of the logic model**
The needs assessment yielded many determinants related to the self-management of our target population. To explore these determinants, two theoretical models were applied that matched and further explained the results of the needs assessment, i.e. the I-Change model, and the transactional model of stress and coping.1021 The overall layout of the intervention is based on the I-Change model21, which helped to decide in what order the determinants arising from the needs assessment should be addressed. However, because the needs assessment showed that the social network plays an important role in diabetes self-management, we combined the social network model of Berkman et al.1 with the I-Change model (figure 2).

The needs assessment also showed that our target population has inadequate coping skills; this represents a challenge for the implementation of self-management behaviours. This finding is in line with other reports on coping and socioeconomic position. Therefore, in our intervention, we decided to emphasize the items ‘Ability factors’ and ‘Barriers’ of the I-Change model. These were extended by replacing them with the transactional model of stress and coping. Again, because the needs assessment stressed the importance of the social network, we extended this model with the social network model of Berkman et al. (figure 3).

In short, the logic model assumes that our target population has a lower quality of life (increased disability/morbidity, increased pain/discomfort, increased depression/anxiety) due to long-term health problems (high morbidity, diabetes-related complications, increased risk for cardiovascular disease, and negative psychosocial outcomes such as high depression rate/stress). These long-term health problems are
FIGURE 1 | Results of the needs assessment: the logic model.
related to poor self-management behaviours and ineffective coping skills caused by external determinants (social engagement/support/influences) and personal determinants (negative outcome expectations, perceived cultural norms and social expectations, moral norms, low risk perception, lack of practical knowledge, low self-efficacy, inadequate use of social network resources, and inability to expand social network with diabetes-related resources). It was also expected that the barriers (both external and personal) would be related to more distant determinants (such as unemployment, poverty, marginalisation) and other societal factors (in our original logic model) that might also influence long-term health problems. However, as Intervention Mapping stipulates focusing on the most important/changeable determinants, it was decided not to include these distant determinants but to consider them as the contextual environment in which the patients live. Although it is beyond the scope of this chapter to describe all the results of the needs assessment, the above-mentioned determinants are in accordance with earlier studies on people with diabetes living in lower socioeconomic neighbourhoods.

Therefore, here we describe only the most distinctive/new features of the intervention, i.e. specifically focusing on the social support/social influences affecting self-management, and on the educational requirements of these patients from a socioeconomically deprived neighbourhood.

1.3.1 the social network and self-management behaviours
Diabetic patients that receive a lot of social support are better able to manage their diabetes than patients that receive little social support. However, the immediate social environment of patients can hinder diabetes self-management. For example, negative interpersonal relationships (distrust, criticism and dominance) also have a major impact on health and health behaviour. Non-supportive behaviours from family members and friends result in lower therapy adherence or lower metabolic control, and too much support (albeit intended by significant others) can be experienced as a form of interference. These social influences might have a stronger impact on health than social support alone. There are indications that this is especially the case among people with lower health literacy. This stresses the need to examine the impact of all influences of the social networks of patients on self-management behaviours.

The social networks of individuals in socioeconomically deprived neighbourhoods often consist of persons that are in the same situation as themselves. For example, in the Netherlands, low-income households are often clustered in the same neighbourhoods and work environments. Moroccan, Turkish and Surinamese immi-
Development of the intervention 'Powerful Together with Diabetes'

Social support
- Instrumental & financial
- Informational
- Appraisal
- Emotional

Social engagement
- Physical/cognitive exercise
- Reinforcement of meaningful social roles
- Bonding/interpersonal attachment
- 'Handling & grooming' effects

Social influence
- Constraining/enabling influence on health behavior
- Norms towards help-seeking behavior
- Peer pressure
- Social comparison process

Awareness factors
- Knowledge
- Cues to action
- Risk perception

Motivational factors
- Attitude
- Social influence (perceived social support, social influence, social engagement)
- Efficacy

Intention state
- Pre-contemplation
- Contemplation
- Preparation

Barrier

Ability factors
- Action plans
- Skills

Health Behavioral Pathways
- Smoking
- Alcohol consumption
- Diet
- Exercise

Physiologic Pathways
- Hypothalamic-pituitary-adrenal response
- Allostatic load
- Immune system functioning
- Cardiovascular reactivity

Self management skills
- Self-monitoring of blood glucose
- Medication use
- Treatment adherence
- Help-seeking behavior

FIGURE 2 | The I-Change model combined with the social network model of Berkman et al.1
grants often live in neighbourhoods and work in environments consisting mainly of people with the same non-Western ethnic background. For people in socio-economically deprived neighbourhoods, the neighbourhood they live in and their family members generally form the most important source of their social contacts.

Social relationships between people that are in the same difficult situation (e.g. situations characterised by exclusion, stigmatisation, and/or poverty) are often strong because of these shared experiences. The social networks they reside in are often smaller and less open than those of people with a higher socioeconomic status. The social networks of people in socioeconomically deprived neighbourhoods often consist primarily of bonding social capital (social interactions between members of a homogeneous social network) and lack bridging social capital (social interactions that allow social network members to access resources other than those in their own social networks).

According to the social network model of Berkman et al., the social network influences health through five mechanisms: i) social support, ii) social influence, iii) social engagement, iv) person-to-person contact, and v) access to resources and material goods.

Social support consists of emotional, instrumental, informational and appraisal support. Social influence consists of constraining/enabling influence on health behaviour, social norms, peer pressure and social comparison processes. Social engagement consists of physical/cognitive exercise, reinforcement of meaningful social roles, bonding/interpersonal attachment, and ‘handling and grooming’ effects. Moreover, the social network approach assumes that not every social network is necessarily beneficial for the health of its members. Also, some social networks are better in promoting health than others, but not everyone has equal access to these social networks.

Small, closed and dense social networks, like those of our target population, might positively influence health because the exchange of social support is often high. However, the strong interdependence between social network members can also prevent members from acquiring new information and ‘getting ahead’ in life. Small social networks are also associated with lower therapy adherence and lower metabolic control. In addition, this type of social network is known to impose strong social norms on its members; when these social norms are incongruent with health behaviours, these social networks often have an adverse influence on the health of its members.
1.3.2 Social network and self-management behaviours in patients from socioeconomically deprived neighbourhoods

Five major themes related to the role of significant others in self-management behaviours emerged from the qualitative data of our needs assessment: i) trying not to bother others, ii) trying not to stand out at social events, iii) peer pressure at social events, iv) social norms regarding medication use and physical activity, and v) having no ‘allies’ in the immediate social environment.

FIGURE 3. Transactional model of stress and coping combined with the social network model of Berkman et al.
Trying not to bother others
Most respondents indicated that they considered their diabetes to be their own responsibility and did not want to bother their significant others (mostly partners, children and friends) with their condition. Most respondents did not see any advantage in asking for social support and indicated that they were capable of managing their diabetes by themselves.

As a result, these respondents often felt ‘bad’ in front of their significant others if they had to take their diabetes into account. For example, some respondents said that they felt sorry for their partners because they always have to set the alarm clock to take their insulin on time, even when their partner wants to sleep. They often did their best not to burden their significant others with their self-management. As a result, our respondents (as well as the participants in the diabetes forum) indicated that they always have to be the stronger person, which demands a lot of self-control.

“I often have to watch my husband eating a whole bowl of custard, cream and chocolate flakes. That’s really difficult, but I don’t want to put him under pressure -- I’m the one who’s sick, not him …” (patient)

The healthcare professionals indicated that relatives often know very little about diabetes and/or the ways to help out with self-management, or they think they are being helpful whereas this is in fact perceived differently by the diabetic patients.

Not asking for support also affected the ability of the respondents to make changes in their self-management. For example, all women from the ethnic minority groups indicated that it is difficult to cook something different, or serve more healthy food, when their significant others do not like it and/or refuse to eat it.

(…when serving brown rice instead of white rice): “Then they ask – what’ve you made now? Coconut?” (patient)

Trying not to stand out during social events
Most respondents were aware that they and their significant others shared the same unhealthy lifestyle. For most respondents, adhering to the diabetes guidelines meant behaving differently from their significant others. Most respondents did not want to draw attention to themselves and their diabetes, i.e. they did not want to stand out in general and especially not during social events.
Particularly the combination of not wanting to bother others and trying not to stand out during social events proved detrimental for their self-management behaviours. When eating at the house of a friend/relative, patients tried to blend in with the others and would not ask the host to take their diabetes into account (e.g. to eat at a certain time, or to make/buy special foods). This often caused uncomfortable situations (e.g. not eating everything that was served, or having to ask for something to eat before dinner) and often required extra self-management skills (e.g. eating in advance, rearranging insulin dosages).

Social gatherings were also experienced as being difficult. The respondents did not want to bother the host with questions about the ingredients or ask him/her to make something especially for them. Therefore, they often did not know what they can/cannot eat. Also, it is difficult to predict how often people might come around offering snacks and what these snacks might contain.

This combination of not asking for support and trying not to cause a fuss also made going out to dinner difficult. Respondents said they sometimes had to wait too long for their food and, because they do not always know what the ingredients are, this makes injecting the right amount of insulin a challenge.

Trying to ‘blend in’ also affected their medication use. Most respondents did their best not to inject insulin during social situations. Some said that the looks from other people made them feel uncomfortable, others said that their relatives did not like to witness an injection (fear of needles), and sometimes asked annoying questions, or interfered too much.

**Peer pressure at social events**

The respondents reported a lot of peer pressure and temptations at social events that affected their diet. Most said that they found it unpleasant when everybody was eating, whilst they either cannot or should not eat that particular food.

For the Turkish, Moroccan and Surinamese respondents, food plays a central role in their daily life. Offering food is seen as a sign of hospitality and it is customary to prepare extra food for guests. Refusing food is seen as impolite. Although respondents knew that they should not accept all the food that is offered, they did not want to hurt anybody’s feelings. Therefore, they often ‘act’ as though they (temporarily) do not have diabetes, or try to avoid these situations as much as possible.
Almost all respondents had difficulty with resisting temptation and often felt pressure to eat unhealthy/too much food, especially in the presence of negative role models.

“... when you’re at a party and other people with diabetes eat really unhealthy things”. Or ‘they’ (people at a party) say: “Well, this one and that one have got diabetes - and it’s OK for them” (patient).

The respondents handle these situations differently: some accept that their blood glucose levels will be too low or too high.

**Social norms regarding medication use and physical activity**
The needs assessment showed that social norms were especially prevalent in medication use. All respondents indicated that they prefer not to take any medication at all. Medications are often regarded as ‘chemicals’ that are not good for their body. Most respondents did not see their medication use as something permanent and hoped that one day they could live without medication. This was confirmed by the healthcare professionals who reported that patients often think that if they lose weight they can live without medication. Most respondents had a strong aversion to insulin and indicated that they definitely did not want to use insulin in the future.

*Then (when you have to use insulin) – that’s when you’re really sick” (patient)*

The interviews with healthcare professionals revealed that Hindustani Surinamese persons often prefer not to take medications and have a strong tendency to see if they can manage without them. They fear that the medications will damage their kidneys; moreover, when they feel unwell they often skip their medication. Especially the use of insulin is experienced as a problem by these patients as it is associated with severe diabetes-related complications. We also observed that Surinamese patients sometimes try to ‘cleanse’ their body by not using medications for a longer period of time. In addition, the interviews showed that Surinamese patients often get advice from other persons not to take their medications but to use ‘nostrums’ (remedies from non-physicians) such as certain herbs or vegetables.

Turkish and Moroccan patients often have doubts about the medications prescribed by their physician. In Morocco and Turkey, physicians generally prescribe more medications and behave in a more authoritative way. Physicians in the Netherlands tend to ask more questions, which is interpreted by patients as lack of competence. The healthcare professionals reported that, after the summer, these patients often
arrive at consultations with a bag of (unnecessary) ‘new’ medications they received from physicians in Morocco or Turkey. They also indicated that, among Moroccan and Turkish men, medications are sometimes associated with impotence.

During Ramadan, 60-80% of Turkish and Moroccan patients is non-adherent to their medications. Individuals who cannot participate during Ramadan due to illness are supposed to compensate by giving money to the poor. However, interviews with professionals revealed that this can be problematic when the individual involved has little/no money. According to the professionals, some alternatives, such as taking food to the poor, are also difficult because this is not socially accepted behaviour in the Netherlands.

Social norms also affect physical activity. For example, Moroccan and Turkish women mentioned they had no money to go to the gym, and that simply ‘walking around’ was not an option for them. They were worried about what people in the neighbourhood might think if they just ‘walked around’ without going anywhere/without a valid reason. This situation was confirmed by the healthcare professionals.

**No ‘allies’ in the immediate social environment**

Most respondents said that they only knew a few people with diabetes and, often, they did not identify with them. For example, these acquaintances had different ways of dealing with their diabetes or were worse off than themselves, making it difficult to exchange ideas, ask questions, or share experiences. This affected multiple self-management domains. Also, quitting smoking was difficult because they were often surrounded by smokers and felt they were the only ones trying to quit.

“… just try stopping when you’re living in a house with five smokers!” (diabetes forum)

Also, especially Dutch respondents said that they did not go to the gym (or go walking) because they had no one to go with, or had no one who thought it necessary to go to the gym.

**1.4 Conclusion**

In conclusion, patients from socioeconomically deprived neighbourhoods generally have social networks that seem less beneficial to self-management because of their small size and the limited ability to acquire new information. Further, the strong social norms these social networks impose on their members seem incongruent with self-management behaviours. Moreover, these patients receive little social support...
for self-management behaviours because they often lack sources of support in their social networks and are reluctant to ask for social support or show others that they need it. These patients find it difficult to deal with influences from their social network such as various temptations, peer pressure, negative role models, and social norms. Moreover, for these patients, some of their significant others are unaware that they can/should help, or they simply do not know how to help.
2. CREATING PERFORMANCE AND CHANGE OBJECTIVES

According to Intervention Mapping, after the needs assessment, matrices of change objectives are created based on the determinants of behaviour and environmental conditions. In these matrices programme planners specify who and what will change as a result of the intervention on different levels (individual level through to the societal level). For each level of performance, objectives are combined with selected personal and external determinants to produce change objectives 2.

We organised two brainstorming sessions with five researchers who studied diabetes, nutrition, overweight and physical activity among patients in lower socio-economic groups, or in minority groups. During these sessions, we checked the content of our performance objectives against their findings and experiences. Then, three researchers who had experience with Intervention Mapping, critically reviewed our performance and change objectives to see if they matched the Intervention Mapping conditions and were suitable to build our intervention on. Based on these meetings, our performance objectives were adjusted where necessary.

2.1 Performance and change objectives

This section focus on the performance and change objectives that were formulated to achieve the health-promoting behaviours for the social network. As described in Section 1, the needs assessment showed that our target population encountered influences that affected their self-management within their social networks (bonding social capital), including a lack of social support, peer pressure, and social norms, but also experienced difficulties in accessing other resources (bridging social capital) outside their social networks, such as new information, an ally/buddy, and other positive role models. In addition, they did not make adequate use of the social network resources already present in their social networks (asking for support, not dealing adequately with peer pressure, social influences and negative role models).

Therefore, based on the needs assessment and consultations with the experts, it was decided that our intervention should not only focus on the patient and their immediate social environment (bonding social capital), but also on bringing patients with diabetes in contact with fellow patients (bridging social capital) thereby extending their social networks with diabetes-related resources. We aimed to extend the participants’ social networks with more diabetes-related resources while simultaneously making their own social networks more diabetes-friendly.

Accordingly, the following health-promoting behaviours were formulated for the
social network that should be achieved by participation in the intervention:

1. Extend the participants’ diabetes-related social networks, facilitating the exchange of social support and positive social influences with group members,
2. Increase the participants’ ability to handle social influences that hinder their self-management such as norms, peer pressure, and temptations,
3. Increase the engagement and support of the participants’ significant others in their self-management.

The health-promoting behaviours for the social network were translated into performance objectives and change objectives. These performance and change objectives are briefly described below in order to give an idea of how these objectives for the social network fit within the total intervention.

Performance and change objectives were formulated for the most important self-management behaviours (i.e. diet, medications, blood glucose monitoring, physical activity and smoking) according to our needs assessment and other theories, e.g. the theory of self-regulation, different self-management theories, and the transactional model of stress and coping, relapse prevention, and social learning theories. Based on the needs assessment, the intervention was divided in two phases. The performance objectives of phase 1 focused on diabetes self-management whereas those of phase 2 focused on coping skills to maintain the newly learned behaviours from phase 1.

The performance and change objectives were formulated on four levels:

1. the participant,
2. the participant in relation to their significant others,
3. the significant others,
4. the participant’s support group as part of the intervention

Table 1 (addendum 2) provides an overview of the performance objectives for the entire intervention. The health-promoting behaviours of the social network are formulated as goals (performance objectives) but also as objectives for determinants supportive of self-management behaviours (change objectives).

Tables 2.1-2.3 (addendum 3) provide an example of the change objectives for the performance objective ‘Patient adequately monitors his/her blood glucose levels’, ‘Patient explains obstacles during monitoring of blood glucose levels to significant others’ and ‘Significant others support patient with adequate monitoring of blood glucose levels’ (levels 1-3). Because we anticipated challenges in the group process of the intervention (which was a key aspect of this intervention) we also formulated performance and change objectives for level 4, i.e. the participant’s support group as part of the intervention (table 2.4, addendum 3).
3. SELECTING THEORETICAL METHODS AND PRACTICAL STRATEGIES

For this intervention, the practical strategies and programme components were developed together with a psychologist who has considerable experience in working with socioeconomically deprived groups. When selecting theory-informed intervention methods/practical strategies and producing programme components/materials, the literature and other ongoing lifestyle interventions were scrutinised for methods and strategies that would be suitable for our target population. These practical strategies/programme components were submitted twice to a panel of migrant health workers with a Turkish, Moroccan and Surinamese background (n=6). In addition, panel members were consulted individually about the specific cultural groups in our target population. Finally, some of the intervention components were pre-tested among the target population by means of focus group discussions (n=3) in which we ‘practiced’ some of the intervention components.

Section 3 describes the conditions/considerations emerging from the needs assessment that are related to health-promotion interventions in patients from a socioeconomically deprived neighbourhood. Then, we describe the ways we considered the results of the needs assessment regarding our methods/strategies in general, because these choices affect all subsequently chosen methods/strategies, including those specific for the health-promoting behaviours of the social network. Section 3 concludes with a description of the methods and strategies specific for the health-promoting behaviours of the social network.

3.1 Considerations regarding health promotion in patients from socioeconomically deprived neighbourhoods

The needs assessment indicated various considerations that need to be taken into account when developing a group-based intervention for patients from socioeconomically deprived neighbourhoods.

The respondents often had busy lives: they spend a lot of time taking care of their family (e.g. grandchildren, chronically ill relatives) and/or working. Some respondents felt stressed due to financial problems, or problems with raising their (teen-age) children, or were worried about relatives living abroad. This was confirmed by the healthcare professionals who reported that these patients often had difficult lives before the additional problem of developing diabetes.
“You’re already having a tough time - then you also get one of the most difficult diseases that exist” (healthcare professional)

Because of this, their disease was often given a low priority. Although they did what they had to do for their diabetes, most did not actively seek information about diabetes themselves. Some respondents expressed the desire for the diabetes nurse or the dietician to simply tell them what they had to do. According to the respondents, the diabetes regime is always complicated because one has to constantly think about the choices to be made and it is never simply ‘yes’ or ‘no’. The healthcare professionals stated that these patients do not necessarily want lots of medical information about their disease, but mainly want to know what they have to do and what they cannot do.

Secondly, the interviews revealed that most respondents have a low level of education, i.e. the majority had attained no, or only one, diploma. They had little learning experience, or their learning experiences were mostly negative, e.g. being unable to follow the classes, or being bored during lessons. These respondents were not convinced that ‘education’ would help them to better understand their diabetes; they said that they were not suitable to learn things, or that ‘learning was not really their thing’. From our observations during the intervention ‘Dealing with diabetes’ we knew that most participants had little experience with following classes. The more traditional educational methods (e.g. the teacher talks and the audience listens) did not seem suitable for this population, e.g. they had a short attention span and became distracted when they did not understand the information presented. Instead of asking questions, the participants generally chose to focus on something else (e.g. their telephones, or other participants).

Moreover, reading and writing was often a challenge for these respondents; this was confirmed by the interviews with the professionals. Also, the level of knowledge about diabetes differed between the respondents; some were unable to name one thing they had to do for their diabetes and could not recall whether they had ever heard of high/low blood glucose levels, whereas others could distinguish between their medications and also explain the basics of diabetes.

The needs assessment also revealed factors that might be important for the group process during the intervention. Most respondents were rather direct/blunt when we first met them (‘rough diamonds’); however, this type of attitude can be problematic in a group where everybody needs to feel safe in order to speak freely. Moreover, it
may be a challenge to find a balance between dealing with one’s problems in daily life whilst also focusing on the aims of the intervention.

3.2 Methods and strategies specific for patients from socioeconomically deprived neighbourhoods

According to the needs assessment, during interventions for patients from socio-economically deprived neighbourhoods, the following aspects should be taken into account: low outcome expectations regarding education and low motivation for education; a low priority for diabetes; a desire for practical information; reading and writing difficulties; and differences in knowledge about diabetes.

From the needs assessment we knew that our target population had little (or primarily negative) experiences with education. Therefore, when selecting our theoretical methods we aimed to make learning as much fun and as interesting as possible. The aim was to make our participants curious about diabetes-related topics and make participation a positive experience by focusing on the abilities of our participants rather than on their shortcomings.

One of our strategies included an inductive educational approach. In contrast to deductive education which stems from theory, inductive education is built from the students’ experiences. Instead of telling students what they need to know from a theoretical point of view (deductive approach), we let the students practice with a problem they can relate to and slowly add information and theory to their understanding (inductive approach). Using this approach, the group leader can also investigate what the participants already know and which knowledge is incorrect or new (since the amount of foreknowledge about diabetes differed). Therefore, an inductive approach focuses on the abilities of the students and is closely connected with their interests. An example of the inductive approach is the game about nutrition: the participants had to solve a puzzle (what foods are green, which are orange and which are red?) together. The aim was to let them brainstorm together, focus on what they already knew, let them discover themselves what they did not know, and add to their knowledge and understanding where necessary.

To make learning as much fun as possible, it was important that the participants did not feel as though they were students but, nevertheless, felt that they benefited from each meeting. At the beginning and during the intervention, it was emphasised that they could help other participants with their own experiences and feedback (participatory problem solving). We did not use traditional educational strategies (such as teaching in front of a classroom) but non-traditional intervention strategies...
such as games and roleplaying, with (fun or relaxing) energisers to optimise the attention span. The participants were encouraged to relate what they would ‘take home’ from the intervention to help them realise what they had learned, or their particular significance for the other participants.

We also focused on self-affirmation by accentuating the personal qualities of the participants. This is a method to stimulate cognitive developments and avoid dismissive/defensive reactions towards information perceived as a threat, and makes participants more perceptible for new information. Practical strategies included giving each other compliments and constructive feedback, energisers, and sharing the positive news of the week at the start of each meeting.

To ensure a close connection to the interests of our participants, we involved them in the intervention through active learning in order to increase relevance and interest. This meant that the participants had direct influence on the topics and rehearsal situations addressed during the intervention.

Because most participants had a low educational background and problems with reading/writing, it can be difficult for them to learn/remember new information. Therefore, we used practical educational methods which enabled participants to remember the provided information and to practice real-life situations. Practical strategies included skills training with guided practice and feedback (practising situations) and ‘chunking’. Also, a limited amount of information was provided at each meeting, and information from the previous meeting was always repeated at the latest meeting. In phase 2 the participants had to plan coping responses with the help of an action plan; this plan mainly consisted of the use of stickers and pictures.

Finally, to anticipate the varied and compelling priorities of our participants, the methods and strategies applied in this intervention focused on dealing with difficult situations that affected self-management; this was to promote/ensure long-term results. Therefore, the focus was on skills training with guided feedback. For example, participants exercised in their own neighbourhood, and went to their own supermarket with a dietician to select healthy foods. Barriers that were encountered (e.g. an unsafe neighbourhood, the higher costs of healthy food) were dealt with during these outings (e.g. exercising while shopping for groceries, finding alternatives that are also healthy, etc.).
3.3 Methods and strategies for the social network

The needs assessment indicated that for interventions using group processes, it is important to consider how to shape these group processes for the participants. It is also important to consider how to balance dealing with personal problems and the goals of the intervention. Moreover, participants might have personal characteristics that can hinder the use of the group process during the intervention. Table 3 (addendum 4) presents an overview of the methods and practical strategies for the health-promoting behaviours for the social network.

For this intervention to be successful it was important that the participants became a mutual support group, i.e. support each other and positively influence each other in self-management behaviours. Therefore, during the intervention we focused on the group process and on establishing a safe learning environment, by increasing trust and the exchange of emotions/experiences between participants. The methods used to achieve this included team building and human relations, stimulating communication and mobilising social support, and skills training for providing and mobilising social support. Participants made agreements about trust, and also agreed to treat the experiences/stories shared within the group in a confidential way. They participated in interactive games in which they had to team-up and form alliances. During the intervention, they established shared goals (e.g. making a cookbook together), were encouraged to share personal stories (e.g. by relating their positive news of the week), and the energisers were aimed at getting to know each other, having fun together, and appreciating each other (e.g. by giving each other compliments). Group members practiced giving constructive feedback and giving/receiving social support before implementing this in real-life situations.

The second goal was to increase the participants’ abilities to handle the social influences that hindered their self-management. Methods included: influencing normative beliefs by making peer expectations visible, building resistance to social pressure, modelling, and vicarious reinforcement. Practical strategies focused on making social influences on self-management visible by means of group discussions and stories about role models. Further, strategies included helping fictional people with self-management problems, followed by giving advice to/asking advice from fellow group members. In phase 2 the participants made an action plan that focused on how to manage their diabetes within their social environments together with group members; in addition, they practiced the skills needed for implementing this action plan during roleplaying exercises, followed by feedback from the group members and group leader.
Finally, the intervention aimed to increase the engagement and support of significant others in self-management behaviours. Methods to achieve this included self-reevaluation, stimulating communication and mobilising social support, modelling, and participatory problem solving. Practical strategies included group meetings for significant others, in which the significant others learned the difference between supportive and non-supportive behaviours, communication skills, and how they might contribute towards self-management. Other strategies included the social network therapy sessions in which the patient and their significant others made an action plan together, which specified what each of them could do to achieve the joint goals.

4 INTERVENTION LAYOUT

The intervention was developed based on the needs assessment which stipulated an intervention that focused on i) the current social networks the patients reside in (less beneficial to self-management behaviours, little new information, strong social norms), ii) acquiring social support from significant others and fellow patients, and iii) dealing with hindering social influences that impact on self-management behaviours (temptations, negative role models, peer pressure and social norms).

Section 4 describes the way the intervention was set-up for the participants. *Powerful together with diabetes* is a group intervention that lasted 10 months and consisted of 32 meetings: i) 24 for participants (10 per group), ii) 6 for their significant others, and iii) 2 social network therapy sessions which was attended by the participants and their significant others. These three components are described separately below.

4.1 Meetings for participants

**Phase 1**

Phase 1 focused on providing the participants with the basic tools to manage their diabetes. During this phase that lasted 3 months, participants came together every week for 2 hours in a community centre (within walking distance from their homes) under the supervision of a group leader. Each meeting centred around one topic: Table 4 presents an overview of the topics.

In phase 1, recurring programme components were: question time, sharing positive news, sugar disease game, nutrition game, letter of the week, roleplaying, energisers, exercising, weighing pros and cons, homework, cookbook, summarising results, and complimenting the participants. These components were adapted to
the gender and cultural background of the different groups (e.g. letter of the week for the Surinamese patients could be about combining medications with nostrums; for Moroccan and Turkish women it could focus on the fear of becoming addicted). Table 5 lists these programme components.

### TABLE 4. Overview of the topics in the meetings for participants: Phase 1.

<table>
<thead>
<tr>
<th>Meeting</th>
<th>Topic</th>
<th>Content of meeting</th>
</tr>
</thead>
</table>
| 1 | What is diabetes? | • Getting to know each other (energiser)  
• Glucose, insulin and the origin of diabetes (sugar disease game)  
• Watching a DVD |
| 2. | Blood glucose levels | 2.1 Blood glucose levels  
• Review of the last meeting and exchange of experiences  
• Collection of questions  
• Information about high and low blood glucose levels (sugar disease game)  
• Exchanging experiences and advice about recognising and dealing with high/low blood glucose levels (letter of the week)  
• Exchanging advice and practicing together how to deal with fear of getting a high/low blood glucose levels (letter of the week and roleplaying)  
• DVD  
• Walking with group members |
| 2. | Monitoring of blood glucose levels | 2.1 Monitoring of blood glucose levels  
• Review of the last meeting and exchange of experiences  
• Collection of questions  
• Weighing the pros and cons of monitoring blood glucose levels because they might be too high (letter of the week)  
• Practising and exchanging advice together about monitoring of blood glucose levels in company (letter of the week and roleplaying)  
• Walking with group members |
| 3 | Medications | 3.1 Medications  
• Review of the last meeting and exchange of experiences  
• Collection of questions  
• Weighing the pros and cons of medication use (letter of the week)  
• Exchanging experiences and advice about difficulties adhering to medication guidelines (roleplaying)  
• Exchanging experiences and advice about how to deal with forgetting medications (letter of the week)  
• Information about medications (sugar disease game)  
• Walking with group members |
| 3.2 Medications | 3.2 Medications  
• Review of the last meeting and exchange of experiences  
• Visit from a diabetic nurse: opportunity to ask questions about own medications (participants brought own medications to the meeting)  
• Exploring own medications with diabetic nurse: what are the different medications for? how to use these medications?  
• DVD  
• Information on influence of medications on blood glucose levels when exercising heavily, when ill, when forgetting medications (sugar disease game)  
• Walking with group members |
### TABLE 4. Overview of the topics in the meetings for participants: Phase 1. (continued)

<table>
<thead>
<tr>
<th>Meeting</th>
<th>Topic</th>
<th>Content of meeting</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Diet</td>
<td></td>
</tr>
<tr>
<td>4.1</td>
<td>Diet 1&lt;br&gt;Mt 2 for significant others</td>
<td>• Review of the last meeting and exchange of experiences&lt;br&gt;• Collection of questions&lt;br&gt;• Information about a healthy diet (nutrition game)&lt;br&gt;• Doing groceries (information on labels/explanation of logos)&lt;br&gt;• Walking with group members</td>
</tr>
<tr>
<td>4.2</td>
<td>Diet 2</td>
<td>• Review of the last meeting and exchange of experiences&lt;br&gt;• Exchange of experiences and advice about barriers to eating healthy&lt;br&gt; (letter of the week and roleplaying)&lt;br&gt;• Walking with group members</td>
</tr>
<tr>
<td>4.3</td>
<td>Diet 3</td>
<td>• Review of the last meeting and exchange of experiences&lt;br&gt;• Exchange of experiences and advice about resisting temptations&lt;br&gt; (letter of the week)&lt;br&gt;• Practising and exchanging advice together about resisting food in&lt;br&gt; social situations (letter of the week and roleplaying)&lt;br&gt;• Eating at regular intervals (group discussion)&lt;br&gt;• Walking with group members</td>
</tr>
<tr>
<td>4.4</td>
<td>Diet 4&lt;br&gt;Mt 3 for significant others</td>
<td>• Review of the last meeting and exchange of experiences&lt;br&gt;• Visit from a dietician: group members can choose between visiting&lt;br&gt; a supermarket (how to pick healthy food from all the labels, how to&lt;br&gt; read food labels), or adjusting their recipes to make them healthier&lt;br&gt;• Recipes: cookbook&lt;br&gt;• Walking with group members</td>
</tr>
<tr>
<td>5</td>
<td>Exercise</td>
<td></td>
</tr>
<tr>
<td>5.1</td>
<td>Exercise 1</td>
<td>• Review of the last meeting and exchange of experiences&lt;br&gt;• Weighing the pros and cons of physical activity&lt;br&gt;• How much do I exercise (group exercise)?&lt;br&gt;• How can we incorporate physical activity into our daily lives?&lt;br&gt;• Walking with group members</td>
</tr>
<tr>
<td>5.2</td>
<td>Exercise 2</td>
<td>• Review of the last meeting and exchange of experiences&lt;br&gt;• Exchanging experiences and advice on how to deal with peer&lt;br&gt; pressure not to exercise (letter of the week)&lt;br&gt;• Practising and exchanging advice on strategies to overcome peer&lt;br&gt; pressure regarding exercise (roleplaying)&lt;br&gt;• Walking with group members</td>
</tr>
<tr>
<td>6</td>
<td>Module of choice</td>
<td>• Review of the last meeting and exchange of experiences&lt;br&gt;• Participants can choose one of the following modules: Diabetes on&lt;br&gt; holiday, Diabetes and Ramadan, Smoking and/or Sexual problems</td>
</tr>
<tr>
<td>7</td>
<td>Celebration: end of phase 1</td>
<td>• Review of the last meeting and exchange of experiences&lt;br&gt;• Looking back at phase 1&lt;br&gt;• Graduation phase 1: diploma</td>
</tr>
</tbody>
</table>
## TABLE 5. | Programme components: Phase 1.

<table>
<thead>
<tr>
<th>Programme components</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review last meeting and exchange of experiences (10-15 min)</td>
<td>At the start of each meeting, the group leader discusses how the period since the last meeting has been, and how the participants worked on their homework. Participants were stimulated to ask questions, exchange experiences, and help each other with their homework.</td>
</tr>
<tr>
<td>Collection of questions (5-10 min)</td>
<td>To guarantee that the meeting fits the needs of the participants, the group leader starts with a short description of the meeting and writes down the participants’ questions on this topic. At the end of the meeting the group leader checks whether all questions have been answered.</td>
</tr>
<tr>
<td>Sharing positive news (5 min)</td>
<td>To make participants more open for new information, they share positive news of the previous week with each other (self-affirmation). This news can cover any topic as long as it was experienced as positive by the participant.</td>
</tr>
<tr>
<td>Sugar disease game (15-35 min)</td>
<td>Many meetings include a knowledge game. Participants participate in a quiz or a game, often teaming-up and competing with each other. The group leader only provides the information that participants ask for themselves. The aim is to only provide information needed by the participants and prevent giving an overload of information. The information provided was supported with visual aids from the Netherlands Institute for Health Promotion and Disease Prevention (NIGZ)</td>
</tr>
<tr>
<td>Nutrition game (60 min)</td>
<td>Participants were divided into groups and given plastic cards with photographs of dishes and foodstuffs. The cards are divided into breakfast, dinner, lunch, snacks, beverages and others. Participants can place cards on three different piles: green (eat as often as you like), orange (eat to a limited extent), and red (try to avoid, eat very rarely). They were asked to place each of these cards on the correct pile. Afterwards, participants discussed the correct place for the cards with each other.</td>
</tr>
<tr>
<td>Letter of the week (20-45 min)</td>
<td>This is a fictional letter from ‘someone with diabetes’ who has a problem that needs to be solved. Participants are invited to brainstorm about the problem and help the writer of the letter to solve their problem. The letter of the week was used to uncover participants’ tacit views and provide them with solutions they might be able to use themselves.</td>
</tr>
<tr>
<td>Roleplaying 20 min (on average)</td>
<td>Every meeting included a roleplaying exercise in which participants practised together with some difficult situation. Participants could also provide roleplaying scenarios themselves (e.g. difficult situations with which they were personally confronted). Each exercise ended with the exchange of advice and tricks/ideas the participants could use in their own lives.</td>
</tr>
<tr>
<td>Energisers (5-15 min)</td>
<td>Energisers included passing a ball along and giving the person who fetches the ball compliments, balancing on a balloon to feel all the muscles in the body, playing ‘web of life’ (a game that shows that everybody needs each other), keeping a balloon in the air, etc. The aim of these energisers is to stimulate bonding between group members and to refresh participants so that they are able to absorb new information again.</td>
</tr>
<tr>
<td>Exercising with participants (30 min)</td>
<td>To show the participants how to exercise for 30 min and also let them experience this, each meeting the group leader walks with the participants for 30 min around the neighbourhood (i.e. the participants’ own neighbourhood). The group leaders are instructed to walk among the participants, so they can talk to everyone.</td>
</tr>
<tr>
<td>Weighing pros and cons (15-20 min)</td>
<td>To change outcome expectations, the participants brainstorm about the pros and cons of certain behaviours (e.g. refusing food at a party). This can be done through group discussions, sometimes using a whiteboard to count the pros and cons. The group leader aimed to emphasise the pros to stimulate positive outcome expectations.</td>
</tr>
<tr>
<td>Homework</td>
<td>The participants get homework at the end of each meeting. They were often asked to pay special attention to certain things (e.g. when do you smoke more than usual?) or to try and meet other participants outside of the meetings.</td>
</tr>
</tbody>
</table>
TABLE 5. | Programme components: Phase 1. (continued)

<table>
<thead>
<tr>
<th>Programme components</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cookbook</td>
<td>The recipes of all participants were collected and compiled in a cookbook which was given to the participants during the intervention. The cookbook also contained information about choosing healthy ready-to-eat meals for those participants who did not cook.</td>
</tr>
<tr>
<td>Summarising results and complimenting participants (10 min)</td>
<td>To help participants feel they had spent their time well, had helped each other and learned a lot, at the end of each meeting the group leader summarises what the participants have learned, and tells participants that he/she is proud of them.</td>
</tr>
</tbody>
</table>

Phase 2

Phase 2 focused on providing the participants with a set of (proactive) coping skills. In this phase, the meetings no longer took place every week. Gradually, more time was placed between each meeting thereby stimulating the participants to undertake activities together, without the group leader being present. The aim was to make participants more independent and to stimulate communication and exchange of social support/social influences outside of the regular meetings. The first two meetings were only one week apart; meetings 2-5 took place biweekly; meetings 6-9 took place once every 3 weeks and, finally, meeting 10 took place 4 weeks after meeting 9. Table 6 presents an overview of the topics included in these meetings.

TABLE 6. | Overview of topics in meetings for participants: Phase 2.

<table>
<thead>
<tr>
<th>Meeting</th>
<th>Topic</th>
<th>Content of meeting</th>
</tr>
</thead>
</table>
| 1       | Diaries 1: physical activity, medications and blood glucose levels | • Discussing the pros and cons of keeping a diary  
          |                                                           | • Keeping a diary for exercise, medications and blood glucose (group exercise)  
          |                                                           | • Walking with participants  
          |                                                           |  **Meeting 4 for significant others** |
| 2       | Diaries 2: nutrition and smoking           | • Review of the last meeting; exchange of experiences  
          |                                                           | • Comparing diary for exercise, medications and blood glucose with formal guidelines (group exercise).  
          |                                                           | • Keeping a diary for nutrition and smoking (group exercise).  
          |                                                           | • Walking with group members |
| 3       | Choosing a behavioural goal                | • Review of the last meeting; exchange of experiences  
          |                                                           | • Comparing diary for nutrition and smoking with formal guidelines (group exercise).  
          |                                                           | • Choosing a behavioural goal, action plan part 1 (group exercise)  
          |                                                           | • Walking with group members |
| 4       | Problems and solutions                     | • Review of the last meeting; exchange of experiences  
          |                                                           | • Exploring barriers and thinking of solutions together, action plan part 2 (group exercise)  
          |                                                           | • Walking with group members |
| 5       | Barriers in the immediate social environments | • Review of the last meeting; exchange of experiences  
          |                                                           | • Exploring barriers in the immediate social environment, action plan part 3 (group exercise)  
          |                                                           | • Special attention to feeling guilty about burden on significant others regarding the disease (letter of the week)  
          |                                                           | • Walking with group members  
          |                                                           |  **Meeting 5 for significant others**  
          |                                                           | • Social network therapy session 1 |
### TABLE 6. Overview of topics in meetings for participants: Phase 2. (continued)

<table>
<thead>
<tr>
<th>Meeting</th>
<th>Topic</th>
<th>Content of meeting</th>
</tr>
</thead>
</table>
| 6       | Solutions for barriers in the immediate social environment | • Review of the last meeting: exchange of experiences  
• Exploring solutions for barriers in the immediate social environment, action plan part 4 (group exercise)  
• How to ask for help (letter of the week, brainstorming)  
• Walking with group members |
| 7       | Practising difficult situations | • Review of the last meeting: exchange of experiences  
• How to respond to peer pressure (roleplaying)  
• Asking for help, being assertive (roleplaying)  
• Walking with group members  
• Homework: keeping diaries again |
| 8       | Barriers and solutions part 2 | • Review of the last meeting: exchange of experiences  
• Comparing new diaries and old diaries, action plan 5 (group exercise) and discussing what goes well and what needs to be improved  
• Walking with group members |
| 9       | Coping with difficult situations | • Review of the last meeting: exchange of experiences  
• Thinking ahead and being proactive in solutions  
• Dealing with risky situations in the future, action plan 6 (group exercise)  
• Walking with group members |
| 10      | Plans for the future | • Review of the last meeting: exchange of experiences  
• What are we going to do in the future (group exercise)  
• Dealing with risky situations in the future, action plan 7 (group exercise)  
• Walking with group members |
| 11      | End of the intervention | • Review of the last meeting: exchange of experiences  
• Looking back at phase 2  
• Graduation phase 2: diploma |

Recurring programme components were homework, review of the last meeting and exchange of experiences, keeping a diary, group exercises, making an action plan, energisers, and walking with other group members (table 7).

Review of the last meeting and exchange of experiences, the energisers, and walking with group members are described in Table 4. In phase 2, some of the energisers focused on remembering information from phase 1 through games and/or exercises (e.g. throwing a ball and naming a green food from the nutritional game when catching the ball). Instead of the group leader initiating walking together and determining how long it would take and where they would go, in phase 2 the participants were encouraged to take the initiative. Participants had to choose what they would like to do (e.g. swimming instead of walking) to make them feel more independent and to make walking (with group members) easier.
TABLE 7. | Programme components: Phase 2

<table>
<thead>
<tr>
<th>Programme components</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homework</td>
<td>In phase 2 the homework of the participants consisted of keeping their diaries, working on their behavioural goals and staying in contact with other participants in the weeks that had no intervention meeting.</td>
</tr>
<tr>
<td>Keeping a diary</td>
<td>For this intervention, special diaries were developed for the participants to keep. They consisted of an outline of the days, which the participants could fill in. For filling in we used stickers, drawings or, if possible, writing. For example, for smoking we had stickers of little cigarettes, for physical activity stickers with a '10' on it (for 10 minutes) and stickers with different colours for the medications. The nutrition diaries could be filled in by means of writing or drawing.</td>
</tr>
<tr>
<td>Group exercise 30-45 min</td>
<td>The group exercises consisted of assignments the participants had to do in small groups (3 participants). Their aim was to let the participant practice and ask each other for feedback in a non-threatening environment, before sharing their experiences with the whole group. It also aimed to clarify what the participants were struggling with and to provide the group leader with guidelines for further explanations.</td>
</tr>
<tr>
<td>Weighing pros and cons 15-20 min</td>
<td>To change outcome expectations the participants brainstormed with each other about the pros and cons of certain behaviours (e.g. refusing food at a party). This was done through group discussions, sometimes using a whiteboard to count the pros and cons. The group leader aimed to emphasise the pros to stimulate positive outcome expectations.</td>
</tr>
<tr>
<td>Action plan</td>
<td>The action plan consisted of 6 parts. It contained many pictures and consisted of outlines the participants had to fill in. Participants who could not write were teamed up with someone that could. The participants were not given all parts of the action plan at once, to prevent them from getting discouraged. They received a portfolio in which they added a part of their action plan each meeting; in this way they did not have to face all the work they still had to do, but could see their work growing. Part 1: Choosing a behavioural goal, making it specific, determining who could help with this goal, and thinking of a reward when achieving this goal. Part 2: Determining two important barriers to achieve the behavioural goal (some of the barriers were already listed in the action plan for the participants to mark). For each barrier the participant has to create five solutions (together with group members). Part 3: Determining important barriers in the immediate social environment to achieve the behavioural goal and thinking of solutions. Part 4: Thinking about ways significant others can help with diet, physical activity, taking medications, monitoring of blood glucose levels, and quitting smoking or smoking less. Part 5: Updating action plan according to keeping a diary and comparing this diary with the one filled out in the beginning of phase 2. Part 6: Determining risky situations in the near future (the coming 2 weeks) and making plans to overcome these risky situations. Part 7: Determining two new risky situations in the near future (the coming 2 weeks) and making plans to overcome these risky situations.</td>
</tr>
<tr>
<td>Roleplaying 20 min (on average)</td>
<td>Every meeting contained a roleplaying exercise in which the participants practised together with a difficult situation from their action plan. The participants could also provide roleplaying scenarios themselves (e.g. difficult situations they were confronted with themselves). Each exercise ended with the exchange of advice and tricks the participants could use in their own lives.</td>
</tr>
<tr>
<td>Exercising with participants 30 min</td>
<td>Continuing to walk for 30 min. Each time a different participant was responsible for the content of the exercise, or the route the participants took.</td>
</tr>
</tbody>
</table>
4.2 Meetings for significant others of participants

For the meetings with significant others, each participant was asked to invite two persons that they considered important for their diabetes self-management. In each phase, three meetings were held for significant others during which the diabetic patients were not present.

Phase 1 focused on increasing practical knowledge about diabetes and its treatment. It also aimed to make the significant others believe that self-management is necessary and to create awareness about their important role in this self-management. Phase 2 focused on supporting a relative or friend with managing diabetes. The aim was to make the significant others aware that self-management is a shared responsibility between themselves and the patient, and to make them feel confident to support the patient (self-efficacy and skills).

Generally, we used the same programme components that were used in the group meetings for participants. The programme components were also alternated with energisers. Other programme components (table 8) included letting the significant others experience certain behaviours themselves to help them empathise with the participant.

<table>
<thead>
<tr>
<th>Meeting</th>
<th>Topic</th>
<th>Content of meeting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase 1</td>
<td>1</td>
<td>Sugar disease and blood glucose levels</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Getting to know each other (introduction of participants)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Watching a DVD</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Glucose, insulin and the origin of diabetes (sugar disease game)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Experiencing what it is like to measure blood glucose and thinking of ways to support someone with this (measuring blood glucose, followed by a group discussion)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Homework</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o Reading the leaflet ‘What is diabetes?’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o if they do not know how to use glucagon: ask a relative/friend or pharmacy</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Medication and physical activity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Review of the last meeting: exchange of experiences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Importance of taking medications and of physical activity (letter of the week, and weighing pros and cons)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Brainstorming and exchanging advice about ways to support a relative/friend with taking medications and physical activity (group discussion)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Homework:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>o To be physically active (e.g. by participating in Netherlands in Motion)</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Healthy nutrition</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Review of the last meeting: exchange of experiences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Discussing the importance of healthy eating (weighing pros and cons)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Information about a healthy diet (nutrition game)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Brainstorming and exchanging advice about ways to support a relative/friend with eating healthy (group discussion)</td>
</tr>
</tbody>
</table>
### Phase 2

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>
| 4 | Diaries | • Collection of questions  
• Practising filling in a diary and discussing ways to support someone with filling in a diary (group exercise) |
| 5 | Behavioural goals and improvement points | • Review of the last meeting: exchange of experiences  
• Collection of questions  
• Choosing a behavioural goal (action plan: part 1)  
• Thinking about helpful and non-helpful behaviour (group exercise, weighing pros and cons) |
| 6 |   | • Review of the last meeting: exchange of experiences  
• Exchanging experiences and advice on how to help someone with diabetes regarding different topics: diet, medications, physical activity, smoking, monitoring of blood glucose levels (letter of the week)  
• Module of choice (see Table 1) |

#### 4.3 Social network therapy sessions (participants and their significant others)

In phase 2 both the participant and their significant others participated in two social network therapy sessions. Both sessions lasted about 25 min each and took place at the respondents' home or, if preferred, at the community centre.

During the first social network therapy session, the participant and their significant others determined a behavioural goal the participant could work on. This behavioural goal had to be based on the action plan used in the meetings for participants. Also, together with the group leader, they identified facilitators/barriers to achieve that goal and considered ways that the significant others could contribute to achieving this goal. The session ended with compiling a list of specific agreements that stipulated who will do what, and when, to achieve this goal.

The second social network therapy session evaluated the things that went well and the things that needed to be improved. If necessary, a new/adapted list of agreements was complied.

#### Training and supervision of group leaders

*Powerful Together with Diabetes* was delivered by various group leaders. The Turkish and Moroccan groups consisted of separate groups for men and women, whereas both men and women were included in the Surinamese group. Each group was guided by a group leader who was matched with the participants on ethnicity and gender. The leaders of the Dutch groups were diabetes nurses, GP assistants, and nurse practitioners, whereas the leaders of the Moroccan, Turkish, and Surinamese groups were migrant health workers.
All group leaders received 4 hours of training prior to phase 1 and another 4 hours prior to phase 2. In these training sessions, they participated in some of the intervention components themselves. During the interventions, all group leaders had regular telephonic contact with the researchers; these calls helped with questions about the intervention and also provided practical advice. In this way, any problems were quickly and efficiently solved.

ACKNOWLEDGEMENTS

We would like to thank Laraine Visser-Isles for editing the final draft of this chapter.
REFERENCES

Development of the intervention ‘Powerful Together with Diabetes’


41. Van der Zwaard J. De lusten en lasten van een vriendinnenkring Turkse en Antilliaanse vrouwen over hun sociale netwerk in verband met rondkomen en vooruitkomen. Amsterdam: SWP.


ADDENDUM 1

**Topic list for patients from a socioeconomically deprived neighbourhood.**

**1. Living with diabetes**
- When were you diagnosed with diabetes?
- What do you have to do to keep your diabetes under control on a daily basis?
- How did your life change since the diagnosis?
- What did you find difficult to change? What did you find the most difficult to get used to? Do you still experience difficulties with certain aspects of diabetes self-management? Which aspects? Why?

**2. Self-management**

**Medications**
- Which medications do you take? When do you take these?
- How do you fit your medication use into your daily life? Do you find that difficult?
- Do you always manage to take your medications correctly and on time?
- Could you specify a situation in which you did *not* manage to take your medications? How do you deal with these situations?
- What do you need to take your medications correctly and on time (practical and social support)? What could your significant others have best done in this situation?

**Insulin**
- Do you use insulin? When?
- How do you fit your insulin use into your daily life? Do you find that difficult?
- Do you always manage to take your insulin correctly and on time?
- Can you specify a situation in which you did not manage to take your insulin? How do you deal with these situations?
- What do you need to take your insulin correctly and on time (practical and social support)? What can your significant others do for you in these situations?

**Nutrition**
- In what way(s) did you adapt your nutrition when you were diagnosed with diabetes? Did you find that difficult? Do you still find that difficult?
- Do you manage to eat sufficient healthy foods every day? Do you manage to eat regularly every day? Do you manage *not* to eat too many calories every day?
Chapter 2

- Can you name some obstacles/situations in which it is difficult to manage healthy eating? (e.g. holidays, busy schedules, bad mood)
- How do you deal with situations like these? In these situations, what do you need to be able to eat healthily? What can your significant others do for you in these situations?

**Physical activity**
- Do you exercise more since the diagnosis? How do you experience this?
- Do you manage to get enough exercise every day?
- Can you describe obstacles/situations in which it is difficult to exercise enough? (e.g. holidays, busy schedules, bad mood)
- How do you deal with situations like these? What do you need to get enough exercise in these situations? What can your significant others do for you in these situations?

**Smoking**
- Do you smoke?
- Can you describe obstacles/situations that make it difficult for you to quit smoking?
- How do you deal with situations like these? What do you need so that you won’t start smoking in these situations? What can your significant others do for you in these situations?
- Former smoker: are you ever tempted to start smoking again? In which situations? What do you need so that you won’t start smoking in these situations? What can your significant others do to support you?

3. **Role of significant others (family members, friends, acquaintances)**
- Which people are important for your diabetes self-management?
- What is their role in your diabetes self-management? Do they help or support you? With what? How? How do you experience that?
- For your diabetes self-management, what kind of support do you receive that you really appreciate? With regard to your self-management, what do you appreciate most about your family members and significant others?
- What is it that these people do that makes them supportive of your self-management? What can they do that you find difficult? How do they support you?
- Are you sometimes confronted with beliefs about diabetes that are incorrect? How do you deal with these beliefs? How do these beliefs affect you? Do you behave differently because of these beliefs?
– Do you ever experience difficulties in managing your diabetes when you are with others? Could you describe such a situation? What happens in these situations? How do you feel in these situations? What do you need in these situations?
– Does it ever happen that people in your immediate social environment do not take your diabetes self-management into account? Can you describe such a situation? What happens in these situations? How do you feel in these situations? What do you need in these situations?
– Does it ever happen that family members or friends make it difficult for you to manage your diabetes? Can you describe such a situation? What happens in these situations? How do you feel in these situations? How do you deal with these situations? What do you need in these situations?
## ADDENDUM 2

### TABLE 1. Performance and change objectives of the intervention Powerful Together with Diabetes.

<table>
<thead>
<tr>
<th>Performance objectives</th>
<th>The participant</th>
<th>The participant in relation to their significant others</th>
<th>The significant others</th>
<th>The support group of the participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phase 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Participant deals adequately with diabetes</td>
<td>1. Participant tells significant others which obstacles he encounters with the correct and consistent intake of medications</td>
<td>1. Significant others gather basic information on diabetes</td>
<td>1. Participants in the support group continue to participate</td>
<td></td>
</tr>
<tr>
<td>1.1 Participants know the origins of diabetes</td>
<td>2. Participant tells significant others which obstacles he encounters when managing blood glucose levels</td>
<td>1.1 Significant others attend the meetings that they are invited to attend</td>
<td>2. Participants in the support group experience the atmosphere as positive and pleasant</td>
<td></td>
</tr>
<tr>
<td>1.2 Participants know the basics about what happens in the body</td>
<td>2.1 Participant tells significant others which obstacles he encounters when monitoring blood glucose levels</td>
<td>1.2 Significant others collect new information on diabetes</td>
<td>3. Participants in the support group experience the meetings as fun and informative</td>
<td></td>
</tr>
<tr>
<td>1. Participant is therapy adherent with regard to medications</td>
<td>2.2 Participant tells significant others which obstacles he encounters when dealing with high/low blood glucose levels</td>
<td>2. Significant others support the patient to take insulin correctly and consistently</td>
<td>4. Participants in the support group trust each other and feel safe with each other</td>
<td></td>
</tr>
<tr>
<td>1.1 Participant takes his medications correctly and consistently every day</td>
<td>3. Participant tells significant others which obstacles he encounters when maintaining a healthy eating pattern</td>
<td>3. Significant others support the patient to manage blood glucose levels</td>
<td>5. Participants in the support group share experiences with each other</td>
<td></td>
</tr>
<tr>
<td>1.2 Participant takes his insulin correctly and consistently every day</td>
<td>3.1 Participant tells significant others which obstacles he encounters when eating sufficient healthy foods</td>
<td>4. Significant others support the patient to correctly monitor blood glucose levels</td>
<td>6. Participants in the support group listen to each other</td>
<td></td>
</tr>
<tr>
<td>2. Participant optimally manages his blood glucose levels</td>
<td>3.2 Participant tells significant others which obstacles he encounters when eating sufficient healthy foods</td>
<td>4.2 Significant others support the patient to correctly deal with high/low blood glucose levels</td>
<td>7. Participants in the support group respect each other's opinions</td>
<td></td>
</tr>
<tr>
<td>2.1 Participant self-monitors his blood glucose levels correctly and consistently</td>
<td>4.3 Participant tells significant others which obstacles he encounters when maintaining a healthy eating pattern</td>
<td>5. Significant others support the patient to maintain a healthy eating pattern</td>
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</tbody>
</table>
**TABLE 1.** Performance and change objectives of the intervention *Powerful Together with Diabetes.* (continued)

<table>
<thead>
<tr>
<th>Performance objectives</th>
<th>The participant</th>
<th>The participant in relation to their significant others</th>
<th>The significant others</th>
<th>The support group of the participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1</td>
<td>Participant tells significant others which obstacles he encounters when exercising sufficiently</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.2</td>
<td>Participant tells significant others which obstacles he encounters when exercising with the right intensity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.1</td>
<td>Participant tells significant others which obstacles he encounters when not smoking</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.1</td>
<td>Significant others support the patient to exercise sufficiently</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.2</td>
<td>Significant others support the patient to exercise with the right intensity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.1</td>
<td>Significant others support the patient to quit smoking</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phase 2</td>
<td>1. Participant monitors his own behaviour (medications, insulin, nutrition, physical activity and smoking)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2.1 Participant compares his own behaviour with the norm</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>2.2 Participant specifies goals for own behaviour</td>
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</tr>
<tr>
<td></td>
<td>3. Participant indicates obstacles to achieve goals</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>3.1 Participant indicates internal obstacles</td>
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<tr>
<td></td>
<td>3.2 Participant indicates obstacles in immediate social environment</td>
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<td></td>
<td>4. Participant collects possible coping strategies to overcome obstacles when achieving goals</td>
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<tr>
<td></td>
<td>5. Participant chooses coping strategy that fits him and his problem(s)</td>
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<td></td>
<td>6. Participant makes an action plan to implement the chosen coping strategy</td>
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<tr>
<td>1.1</td>
<td>Significant others see diabetes self-management as a shared responsibility</td>
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<tr>
<td>2.1</td>
<td>Significant others regularly ask about how the diabetes self-management is going</td>
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<tr>
<td>2.2</td>
<td>When the diabetes self-management goes well the significant others give the patient compliments</td>
<td></td>
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<tr>
<td>3.1</td>
<td>When experiencing obstacles, the significant others give positive feedback</td>
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<tr>
<td></td>
<td>3. Significant others brainstorm with the participant about the source of these obstacles</td>
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</tr>
<tr>
<td></td>
<td>3.1 Significant others brainstorm with the participant about obstacles within the participant</td>
<td></td>
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</tr>
</tbody>
</table>

1. Participants in the support group form a team
2. Participants in the support group participate in activities together to improve their diabetes self-management (besides the regular group meetings)
3. Participants in the support group keep on supporting each other with their diabetes self-management after the end of the intervention
<table>
<thead>
<tr>
<th>Performance objectives</th>
<th>The participant</th>
<th>The participant in relation to their significant others</th>
<th>The significant others</th>
<th>The support group of the participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.</td>
<td>Participant carries out the action plan</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>8.</td>
<td>Participant evaluates the action plan and adjusts it when necessary</td>
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</tr>
<tr>
<td>8.1</td>
<td>Participant evaluates the action plan</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.2</td>
<td>Participant adjusts the action plan when necessary</td>
<td></td>
<td></td>
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<tr>
<td>9.</td>
<td>When experiencing a relapse, the participant interprets this positively (not as a failure) and goes back to 3</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>9.1</td>
<td>Participant interprets relapse positively</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.2</td>
<td>Participant goes back to 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.1</td>
<td>Significant others brainstorm with the participant about obstacles outside the participant</td>
<td></td>
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</tr>
<tr>
<td>8.1</td>
<td>Significant others choose a constructive strategy to overcome these obstacles together with the participant</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>8.2</td>
<td>Significant others choose a suitable strategy with the participant</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Significant others make agreements with the participant</td>
<td></td>
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</tr>
<tr>
<td>5.1</td>
<td>Significant others concur with the participant on agreements about asking for and receiving support</td>
<td></td>
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<tr>
<td>6.</td>
<td>Significant others keep these agreements</td>
<td></td>
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</tr>
<tr>
<td>7.</td>
<td>Significant others evaluate these agreements and adjust them when necessary</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>7.1</td>
<td>Significant others evaluate the agreements together with the participant</td>
<td></td>
<td></td>
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<tr>
<td>7.2</td>
<td>Significant others adjust the agreements with the participant when necessary and go to 2.1</td>
<td></td>
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<tr>
<td>8.</td>
<td>Significant others avoid using punitive remarks when the participants experience a relapse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.1</td>
<td>Significant others avoid punitive remarks</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.2</td>
<td>Significant others go to 2.3</td>
<td></td>
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</tr>
</tbody>
</table>
### TABLE 1. Performance and change objectives of the intervention *Powerful Together with Diabetes.* (continued)

<table>
<thead>
<tr>
<th>Performance objectives</th>
<th>The participant</th>
<th>The participant in relation to their significant others</th>
<th>The significant others</th>
<th>The support group of the participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Participant identifies future risk situations for his diabetes self-management</td>
<td>Same as above</td>
<td>Same as above</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Participant chooses the most suitable coping strategies to prevent these risk situations turning into a relapse</td>
<td></td>
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<tr>
<td>3. Participant makes an action plan</td>
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<tr>
<td>4. Participant implements the action plan before encountering high-risk situations</td>
<td></td>
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<tr>
<td>5. Participant evaluates his coping strategy and adjusts it when necessary</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.1 Participant evaluates his coping strategy</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>5.2 Participant adjusts the action plan when necessary and goes back to 4.</td>
<td></td>
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</tr>
</tbody>
</table>
### ADDENDUM 3

#### TABLE 2. Example of change objectives.

#### 2.1 The participant

<table>
<thead>
<tr>
<th>Performance objective</th>
<th>Personal determinants</th>
<th>External determinants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Attitude, outcome expectations</td>
<td>Perceived (cultural) norms and social expectations</td>
</tr>
<tr>
<td><strong>Participant monitors blood glucose levels correctly and consistently</strong></td>
<td>Participant expects that monitoring his blood glucose levels correctly and consistently will provide more control and security.</td>
<td>Participant regards monitoring blood glucose levels correctly and consistently as a part of daily life.</td>
</tr>
<tr>
<td></td>
<td>Participant expects that he will understand his body better by monitoring blood glucose levels.</td>
<td>Participant realises that monitoring blood glucose levels is more important than trying to fulfill social expectations.</td>
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</tbody>
</table>
### 2.2 The participant in relation to their significant others

<table>
<thead>
<tr>
<th>Performance objective</th>
<th>Attitude, outcome expectations</th>
<th>Perceived (cultural) norms and social expectations</th>
<th>Moral norms</th>
<th>Self-efficacy and skills</th>
<th>Social support</th>
<th>Social influence</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1 Participant tells his significant others which obstacles he encounters when monitoring his blood glucose levels</td>
<td>Participant expects that informing his significant others will not affect his autonomy, but will make monitoring blood glucose levels correctly and consequently easier</td>
<td>Participant realises that his significant others might influence the management of his blood glucose levels: - Asking annoying questions - Giving funny looks or being disgusted - Acceptance of monitoring - Not being helpful with high or low blood glucose levels</td>
<td>Participants regards informing his significant others as a part of his responsibilities</td>
<td>Participant is confident to dare and to be able to inform his significant others about the obstacles he encounters when monitoring his blood glucose levels Participant is able to show how to inform his significant others about the obstacles he encounters when monitoring his blood glucose levels</td>
<td>Participants in the support group help with thinking about the best ways to inform each other’s significant others about the obstacles they encounter when monitoring their blood glucose levels Significant others indicate that they are interested in the obstacles the participant encounters when monitoring his blood glucose levels</td>
<td>Participants in the support group encourage the participant to inform his significant others about the obstacles he encounters when monitoring his blood glucose levels Participants in the support group exchange positive experiences with informing significant others about the obstacles they encounter when monitoring their blood glucose levels Participants in the support group inform their significant others (positive example for other group members) about the obstacles they encounter when monitoring their blood glucose levels</td>
</tr>
<tr>
<td></td>
<td>The participant expects that informing his significant others will enable them to better support him when monitoring his blood glucose levels</td>
<td>The participant realises that his significant others cannot take his needs into account if he does not inform them</td>
<td></td>
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</tbody>
</table>
### 2.2 The participant in relation to their significant others (continued)

<table>
<thead>
<tr>
<th>Personal determinants</th>
<th>External determinants</th>
</tr>
</thead>
<tbody>
<tr>
<td>is wrong: acting as normal as possible). Participant realises that informing his significant others is more important than being afraid of burdening them</td>
<td>Significant others encourage the participant to tell them about the obstacles he encounters when monitoring his blood glucose levels</td>
</tr>
</tbody>
</table>
### 2.3 The participant in relation to their significant others

<table>
<thead>
<tr>
<th>Performance objective</th>
<th>Personal determinants</th>
<th>External determinants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Attitude, outcome expectations</td>
<td>Perceived (cultural) norms and social expectations</td>
</tr>
<tr>
<td>2.1 Participant tells his significant others which obstacles he encounters when monitoring his blood glucose levels</td>
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<td>Participant realises that his significant others might influence the management of his blood glucose levels: - Asking annoying questions - Giving funny looks or being disgusted - Acceptance of monitoring - Not being helpful with high or low blood glucose levels</td>
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</tbody>
</table>

The participant expects that informing his significant others will enable them to better support him when monitoring his blood glucose levels. The participant expects that the burden he will put on his significant others will be acceptable.
### 2.4 The participant’s support group.

<table>
<thead>
<tr>
<th>Performance objective</th>
<th>Personal determinants</th>
<th>External determinants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attitude, outcome expectations</td>
<td>Perceived (cultural) norms and social expectations</td>
<td>Moral norms</td>
</tr>
<tr>
<td>1. Participants in the support group continue to participate in the group meetings</td>
<td>Participants in the support group expect that participation will increase their control over their diabetes</td>
<td>Participants in the support group believe that their group members will also keep on participating</td>
</tr>
<tr>
<td></td>
<td>Participants in the support group expect that participation will motivate them to keep exercising, eat healthy and quit smoking</td>
<td>Participants in the support group feel that they are expected to keep on participating</td>
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<td></td>
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<td>Participants in the support group realise that participating in the support group is more important than fulfilling other social expectations</td>
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</table>
### ADDENDUM 4

**TABLE 3. | Theoretical methods and practical strategies.**

<table>
<thead>
<tr>
<th>General objective</th>
<th>Sub-goals</th>
<th>Theoretical methods</th>
<th>Practical strategies</th>
</tr>
</thead>
</table>
| 1. Extending participants’ diabetes-related social networks, facilitating the exchange of social support and positive social influences with group members. | - Participants positively influence each other (role models, positive peer pressure, positive group norms).<br>- Participants encourage and support each other in adhering to their self-management during the intervention, and continue to support each other after the intervention has ended (advice, helping each other).<br>- Participants continue to see each other after the intervention, and continue to do DSM-related activities together (e.g. exercising). | Skills training for providing and mobilising social support<br>Participatory problem solving<br>Conscientisation methods<br>Team building and human relations<br>Stimulating communication and mobilising social support | **Group meetings for people with diabetes: Phases 1 and 2**<br>- Participants took part in interactive games and energisers (short breaks during the intervention in order to keep the participants motivated and concentrated during the rest of the programme: energisers often consisted of short exercises aimed at group bonding, e.g. throwing a balloon back and forth while giving each other compliments) in which they had to team up with someone or form alliances. They were encouraged to open up to each other through these games and energisers.  
- Participants were regularly invited to talk about their self-management problems and to ask group members for advice. To do this, the group members learned skills for giving constructive feedback.  
- In small subgroups, participants did assignments in which they had to help each other (e.g. adjusting recipes together) to get used to giving and receiving social support.  
- Participants had shared goals during the intervention such as making a cookbook together and attaining their diplomas.  
- Participants were encouraged to phone and/or meet up with each other outside of the group meetings.  
<p>| <strong>Group meetings for people with diabetes: Phase 2</strong>&lt;br&gt;- Periodic (first two weekly, then monthly) meetings were held. Participants were encouraged to continue seeing each other in between group meetings without the group leader. |</p>
<table>
<thead>
<tr>
<th>General objective</th>
<th>Sub-goals</th>
<th>Theoretical methods</th>
<th>Practical strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Increasing participants' abilities to handle social influences that hinder their self-management, such as norms, peer pressure, and temptations.</td>
<td>- Participants critically evaluate the impact significant others have on their OSM.</td>
<td>Influencing normative beliefs by making peer expectations visible</td>
<td>Group meetings for people with diabetes: Phase 1</td>
</tr>
<tr>
<td></td>
<td>- Participants are better able to deal with social influences that hinder their self-management, such as peer pressure (e.g. pressure to eat unhealthy foods or to overeat, or negative feedback when exercising or taking medications).</td>
<td>Building resistance to social pressure to engage in risk behaviour</td>
<td>Group discussions were held about social situations in which managing diabetes is difficult (in response to a DVD, a letter of the week, and of their own accord).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Modelling and vicarious reinforcement</td>
<td>Participant practised these strategies with group members during roleplaying exercises.</td>
</tr>
<tr>
<td></td>
<td>Group meetings for people with diabetes: Phase 2</td>
<td></td>
<td>Group meetings for people with diabetes: Phase 2</td>
</tr>
<tr>
<td></td>
<td>- An action plan was drawn up in which social influences and dealing with social influences played an important part (group meetings). Together with other group members, the person with diabetes came up with strategies and solutions to overcome these difficulties.</td>
<td></td>
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</tr>
</tbody>
</table>
### TABLE 3. Theoretical methods and practical strategies. (continued)

<table>
<thead>
<tr>
<th>General objective</th>
<th>Sub-goals</th>
<th>Theoretical methods</th>
<th>Practical strategies</th>
</tr>
</thead>
</table>
| 3. Increasing the engagement and support of the participants’ significant others in self-management. | - Participants ask significant others for support.  
- Participants indicate that their significant others are more involved in their self-management (providing more support or more enabling social influences).  
- Participants experience more enabling social influences.  
- Participants experience fewer social influences from their significant others that hinder their self-management. | Self-reevaluation  
Stimulating communication and mobilising social support  
Modelling  
Participatory problem solving | Group meetings for people with diabetes: Phase 1  
- Participants were encouraged to tell their significant others they have diabetes (if they did not know).  
- Participants were encouraged to tell their significant others about the negative social influences and barriers they face (social network therapy).  
Social network therapy session: Phase 2  
- Participants discussed solutions and strategies with their significant others to deal with negative social influences on self-management.  
- Together with their significant others, participants agreed on an action plan in which the significant others play an active role in their self-management. In this action plan, the participant and his/her significant other(s) described the problem they would be working on and barriers and facilitators to overcome this problem. Finally, they agreed on some concrete appointments with each other to overcome this problem.  
Group meetings for significant others: Phases 1 and 2  
- Significant others learned more about diabetes and the important role they play in the self-management of the patient with diabetes.  
- To change their norms regarding self-management tasks, the significant others critically evaluated their own lifestyles through interactive games. |
<table>
<thead>
<tr>
<th>General objective</th>
<th>Sub-goals</th>
<th>Theoretical methods</th>
<th>Practical strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>- Significant others did interactive assignments in which they distinguished helpful and non-helpful behaviour with regard to self-management.</td>
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<td></td>
<td>- Group discussions were held about ways to better facilitate the self-management of their relative with diabetes.</td>
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<tr>
<td></td>
<td></td>
<td>- Significant others learned ways to ask about their relative's self-management in a friendly, supportive way (group meetings for significant others).</td>
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</tr>
</tbody>
</table>
The DISC (Diabetes in Social Context) Study – evaluation of a culturally sensitive social network intervention for diabetic patients in lower socioeconomic groups: a study protocol

C. Vissenberg
V. Nierkens
P.J.M. Uitewaal
D. Geraci
B.J.C. Middelkoop
G. Nijpels
K. Stronks

Based on:
The DISC (Diabetes in Social Context) Study evaluation of a culturally sensitive social network intervention for diabetic patients in lower socioeconomic groups: a study protocol.

BMC public health 12 (1) 2012:199. DOI: 10.1186/1471-2458-12-199
ABSTRACT

Background

Compared to those in higher socioeconomic groups, patients with diabetes in lower socioeconomic groups have less favourable metabolic control and experience more diabetes-related complications. They encounter specific barriers that hinder optimal diabetes self-management, including a lack of social support and other psychosocial mechanisms in their immediate social environments. Powerful Together with Diabetes is a culturally sensitive social network intervention specifically targeted to ethnic Dutch, Moroccan, Turkish, and Surinamese patients in lower socioeconomic groups. For ten months, patients will participate in peer support groups in which they will share experiences, support each other in maintaining healthy lifestyles, and learn skills to resist social pressure. At the same time, their significant others will also receive an intervention, aimed at maximizing support for and minimizing the negative social influences on diabetes self-management. This study aims to test the effectiveness of Powerful Together with Diabetes.

Methods

We will use a quasi-experimental design with an intervention group (Group 1) and two comparison groups (Groups 2 and 3), N=128 in each group. Group 1 will receive Powerful Together with Diabetes. Group 2 will receive Know your Sugar, a six-week group intervention that does not focus on the participants’ social environments. Group 3 receives standard care only. Participants in Groups 1 and 2 will be interviewed and physically examined at baseline, 3, 10, and 16 months. We will compare their haemoglobin A1C levels with the haemoglobin A1C levels of Group 3. Main outcome measures are haemoglobin A1C, diabetes-related quality of life, diabetes self-management, health-related, and intermediate outcome measures. We will conduct a process evaluation and a qualitative study to gain more insights into the intervention fidelity, feasibility, and changes in the psychosocial mechanism in the participants’ immediate social environments.

Conclusion

With this study, we will assess the feasibility and effectiveness of a culturally sensitive social network intervention for lower socioeconomic groups. Furthermore, we will study how to enable these patients to optimally manage their diabetes.
The DISC (Diabetes in Social Context) Study – evaluation of a culturally sensitive social network intervention for diabetic patients in lower socioeconomic groups: a study protocol

BACKGROUND

Lower socioeconomic (SE) groups are not only disproportionately affected by type 2 diabetes, they also have more diabetes-related complications and higher diabetes-related mortality compared to diabetic patients in higher SE groups. A possible explanation for this could be poorer glycaemic control. Achieving optimal glycaemic control requires the patient to take part in a complex set of tasks: adhering to dietary advice and medications, engaging in regular physical activity, quitting smoking, and monitoring of blood glucose levels, known as diabetes self-management (DSM). These tasks seem to be more challenging for patients in lower SE groups.

Interventions aimed at improving DSM can contribute to better glycaemic control and the prevention of diabetes-related complications. However, there are indications that interventions for the general diabetic population are less suitable for lower SE groups and need to be adapted to the specific barriers they face. Barriers to DSM among lower SE groups include a lack of knowledge of diabetes, low self-efficacy, low perceived control, and low health literacy.

Another mentioned barrier to DSM among lower SE groups is a lack of diabetes-related social support. To maintain lifestyle changes, long-term social support in particular seems beneficial. From other fields such as sociology we know that social support is not the only psychosocial mechanism through which the immediate social environment influences health. Other psychosocial mechanisms are social influences such as peer pressure, norms and social comparison processes, which extend from the social network’s values and norms, and social engagement which defines and reinforces meaningful social roles through network participation. These psychosocial mechanisms may have both negative and positive effects on health behaviour. For example, if the social norms in the immediate social environment are incongruent with DSM, family and/or friends might hinder DSM (intentionally or unintentionally) by providing negative role models or by exerting peer pressure.

Patients in lower SE groups are often surrounded by social networks that seem to have a strong adverse effect on their DSM. These groups often have small, dense
social networks with strong ties that consist primarily of people in similar (low SE) situations to their own, mainly family members and close friends. Their social networks often lack more distant acquaintances, that is, people who move in different circles than their own. These distant acquaintances are needed to introduce resources, information, and ideas that might be missing from their own social networks (such as diabetes related information and role models). These ‘closed’ social networks are known to impose strong group norms on their social network members. Combined with the unfavourable diabetes outcomes among lower SE groups, this may suggest that these groups are confronted with strong psychosocial mechanisms (social support, social influence and social engagement) in their immediate social environments that adversely affect their DSM. This is supported by recent studies which show that lower SE groups experience difficulties in coping effectively with psychosocial mechanisms such as peer pressure, cultural expectations, fewer positive role models, and not having control over their family’s lifestyle choices.

To improve DSM among lower SE groups, it seems important to focus specifically on creating long-term diabetes-related social support, and to target the other existing psychosocial mechanisms such as social influence and social engagement in their immediate social environments that have adverse effects on their DSM. Therefore, we systematically developed a theory-based culturally sensitive social network based intervention targeted to ethnic Dutch, Turkish, Moroccan, and Surinamese patients with diabetes in lower SE groups. Powerful Together with Diabetes (PTWD) aims to improve DSM by stimulating long-term social support and targeting existing psychosocial mechanisms in the immediate social environment that have an adverse effect on DSM. This paper describes the intervention, the theoretical background of this intervention, and the study design.

**METHODS**

**The intervention: Powerful Together with Diabetes (PTWD)**

To develop PTWD, we used the Intervention Mapping method: a systematic approach for designing and evaluating health-promotion interventions. The first step in Intervention Mapping is a needs assessment, followed by creating matrices of change objectives, selecting theory-informed intervention methods and practical strategies, and finally, producing programme components and materials.
For the needs assessment, we examined the existing literature for barriers to DSM among lower SE groups. We also held in depth semi-structured qualitative interviews with diabetic patients (n=21), analysed the content of an internet forum for diabetic patients, and observed the daily practices of a diabetes nurse in a neighbourhood with low socioeconomic status for two days. We created matrices of change objectives with the help of researchers specialized in Intervention Mapping. When selecting theory-informed intervention methods and practical strategies and producing programme components and materials, we examined the existing literature and currently ongoing lifestyle interventions for methods and strategies that would fit our target population. We also submitted our practical strategies and programme components twice to a panel of experts with Turkish, Moroccan, and Surinamese backgrounds (n=6), and consulted them individually with specific questions about the different cultural groups in our target population. Finally, we pretested some of our intervention components among the target population using focus group discussions (n=3).

Because this intervention has to stimulate long-term social support and target existing psychosocial mechanisms in DSM, PTWD will consist of the following three components: 1) group meetings for patients with diabetes, 2) group meetings for the participants’ significant others (e.g. family and/or friends), and 3) social network therapy sessions with the patient and his/her significant other(s). PTWD will last ten months and consist of two phases (see Table 1).

| TABLE 1. Overview of the two phases of Powerful Together with Diabetes |
| Phase 1 (months 1-3) | Phase 2 (months 4-10) |
| Thirteen weekly peer group meetings for diabetic patients. |
| Three group meetings for significant others. |
| Eight twice-monthly peer group meetings for diabetic patients followed by five monthly peer group meetings. |
| Three group meetings for significant others. |
| Two social network therapy sessions for the diabetic patient and his/her significant other(s). |

The intervention will be held in the mother tongue of the participants. We culturally targeted PTWD by changing the outline of the intervention to make it compatible with the ethnic minority participants’ annual visits to their countries of origin and the celebration of Ramadan. We also culturally tailored the content of the intervention components to the different cultural groups, for example, by incorporating sociocultural values and barriers to DSM, and adapting the materials to fit the needs of the different cultural groups.
We describe the intervention components below, including their behavioural goals and the determinants we addressed to achieve these goals. The behavioural goals were based on the theory of self-regulation, different self-management theories, and the transactional model of stress and coping, relapse prevention, and social learning theories. Because targeting psychosocial mechanisms within the immediate social environment of the participants (such as the exchange of social support) plays an important part in this intervention, for every intervention component we also created separate behavioural goals for these determinants.

**Group meetings for diabetic patients**

The diabetic patients will participate in group meetings (ten persons per group) for ten months. In Phase 1 (months 1-3), the participants will be provided with the basic ‘tools’ they need to manage their diabetes. This phase focuses on creating positive outcome expectations and moral norms, increasing knowledge, skills, and self-efficacy, stimulating social support, and recognizing and dealing with psychosocial mechanisms that hinder optimal DSM, such as peer pressure and existing social norms. In Phase 2 (months 4-10), the participants will learn how to put the tools they gathered in Phase 1 to use. They will develop and train DSM skills until they have a solid set of coping skills, which will enable them to optimally manage their diabetes in the long term.

To reach these behavioural goals and change the determinants associated with them, we chose strategies that would fit our target population and their specific needs regarding information processing. For example, by engaging the participants in an interactive diabetes quiz, we aim to increase their practical knowledge about diabetes. We aim to increase DSM skills and self-efficacy through a ‘letter of the week’, in which a fictitious diabetic patient presents a problem and asks the group members for advice. To increase awareness about barriers to DSM (Phase 2), the participants will monitor their own behaviour with the help of specially designed diaries. Through participatory problem-solving and rehearsal situations, we aim to improve the participants’ skills and self-efficacy to overcome these barriers. Due to the large number of behavioural goals, in addendum 1 and 2 we present a representative summary of the behavioural goals, the determinants addressed, and the strategies used in Phases 1 and 2.

Stimulating long-term social support and targeting existing psychosocial mechanisms that have an adverse effect on DSM are important parts of the intervention. Examples of strategies used to stimulate social support are interactive games in which the participants complement each other on their DSM and other subjects.
(self-affirmation), and stimulating the exchange of advice between participants. The participants are also encouraged to see each other outside of the group meetings, and to undertake DSM-related activities together (e.g. participating in an exercise initiative in the neighbourhood). A final aim of the intervention is that the participants will continue to see and consult each other after the intervention has ended.

To stimulate social support and target existing psychosocial mechanisms that have an adverse effect on DSM in participants' immediate social environments, we use role-model stories, rehearsal situations, and homework assignments that focus on these behavioural goals. In addition, the group meetings for the significant others and the social network therapy sessions (see below) will contribute to the achievement of this behavioural goal.

**Group meetings for significant others**

Each diabetic patient will identify one or two persons in his/her immediate environment with a great deal of influence on his/her DSM. These significant others will participate in six group meetings with other significant others: three during Phase 1 and three during Phase 2. The patients will not be present during these meetings.

In Phase 1, we will aim to increase the significant others' knowledge about diabetes and its treatment, make them feel that DSM is necessary and inevitable (outcome expectations and perceived cultural norms), and that they have an important role in the DSM of their relative/friend (perceived cultural norms and self-efficacy). To increase the significant others' knowledge, we will use a short version of the interactive diabetes quiz (which we use in the group meetings for the patients). Using positive role-model stories and shared positive experiences from group members (vicarious reinforcement) and group discussions, we will try to increase positive outcome expectations and positive moral norms towards DSM, and increase awareness about the role of significant others in the DSM of patients.

In Phase 2, we will focus on supporting their relative/friend in managing his/her diabetes. We will aim to make the significant others aware of the fact that DSM is a shared responsibility. Next, we will aim to make them feel confident they can support the patient with his/her DSM (self-efficacy) and be able to effectively support the patient in his/her DSM (skills). By exchanging positive experiences and through communication skills training combined with rehearsal situations and feedback, we will aim to improve the significant others' skills and self-efficacy (see addendum 3). The group meetings will be followed by the social network therapy sessions.
Social network therapy sessions

In Phase 2, the patient and his/her significant other(s) will take part in two social network therapy sessions. With these sessions, we will aim to further stimulate the exchange of social support and diminish negative social influences on DSM. In these sessions, the group leader will lead a discussion between the patient and his/her significant other(s). In the first meeting, they will discuss the ways the patient is currently managing his/her diabetes and how his/her DSM could be improved. Next, they will discuss the ways the significant other(s) can assist the patient in improving his/her DSM. Finally, they will make an action plan to put the things discussed into action. In the second meeting, this action plan will be evaluated and further refined (see addendum 4).

Intervention for the comparison group: Know your Sugar

To evaluate the effects of an extra focus on psychosocial mechanisms and social support in the intervention group, we chose to offer the comparison group a lifestyle group intervention as well. Know your Sugar (KYS) is a group intervention that aims to provide the participants with the information they need to be able to manage their diabetes, and provide them with the opportunity to exchange social support. KYS will not actively focus on social support and the pre-existing psychosocial mechanisms that influence DSM in the participants’ immediate social environments.

KYS consists of six weekly group meetings. It is based on ‘How to deal with diabetes’, a Dutch course originally developed for Turkish patients, and Dutch National Institute for Health Promotion and Disease Prevention (NIGZ) posters (i.e. large visual aids used by diabetic nurses to facilitate explaining and talking about diabetes-related subjects with patients). Both are known as the current best practices in the Netherlands for people with diabetes in lower SE groups. Together they form the foundation of KYS, which we then further developed to make it culturally sensitive for the different cultural groups in our study population. To increase the participants’ knowledge, we will use the same strategies we use in PTWD, but with no extra focus on the exchange of experiences and social support.

Training and supervision of group leaders

PTWD and KYS will be given by different group leaders. The PTWD group leaders will receive a four-hour training prior to Phase 1 and a four-hour training prior to Phase 2. The KYS group leaders will receive a two-hour training prior to the intervention. During the interventions, all group leaders will have regular contact with the researchers by telephone. During these calls they can ask questions about the intervention and get practical advice.
Research questions
This study will aim to answer the following research questions:

What are the effects of the intervention (PTWD) on haemoglobin A1C (HbA1c) compared with the intervention for the comparison group (KYS) and standard care at 3, 10, and 16 months?

1. What are the effects of the intervention on diabetes-related quality of life compared to the intervention for the comparison group at 3, 10, and 16 months?
2. What are the effects of the intervention on health-related outcome measures, diabetes self-management, and intermediate outcome measures compared to the intervention for the comparison group at 3, 10, and 16 months?
3. What is the feasibility of the intervention and the intervention for the comparison group?
4. What is the cost-effectiveness of the intervention compared to the intervention for the comparison group and standard care?

Study design
The intervention effects will be measured in a quasi-experimental controlled trial: the DISC (Diabetes in Social Context) Study. The participants who receive the intervention (PTWD, N=128) will be compared with the participants of the comparison group (KYS, N=128). In addition, the HbA1c levels of the participants in both groups will be compared with the HbA1c levels of 128 diabetic patients who will receive no intervention at all (standard care).

Matching, blinding, recruitment, and informed consent
For the intervention to be successful, it is important that the participants live near each other. Therefore randomisation is impossible. Therefore, the intervention and comparison group will be matched according to ethnicity, gender, and organization of diabetes care. Blinding the general practitioners (GPs) is impossible due to the nature of this study.

Recruiting people and maintaining participation in lower SE groups in intervention studies is difficult due to a low level of trust and insufficient understanding of the study and study procedures. To increase trust and understanding, the eligible patients will be invited to a ‘welcome meeting’ about PTWD or KYS by their GP, a person they trust and respect. For people who do not speak Dutch, we will organise meetings in their mother tongue. At the welcome meetings, the eligible patients will receive detailed information about the study procedures. They will also take part in one of the intervention components (in PTWD groups, a short version of the
game about nutrition, in KYS groups a short version of the diabetes quiz) to get an idea of what the intervention will be like. They will also meet their group leaders and the other patients and will see the intervention location, which we hope will lower barriers to participation.

At the end of the welcome meeting, the participants have two weeks to consider their participation. After two weeks they will be asked to sign an informed consent form in which they agree to participate in the intervention and give their consent for the study procedures. The informed consent form will be read to the patient and further explained if necessary. People who do not speak Dutch will receive the information in their mother tongue.

Ethical considerations
This study has been approved by the Medical Ethics Committee of the Academic Medical Center (AMC) in Amsterdam, and is registered with the Dutch Trial Register (Dutch Trial Register NTR1886).

Study population
We will include people with type 2 diabetes who received medical treatment long enough to achieve optimal glycaemic control (one year) but still have a HbA1c above 7% \(^38\). Inclusion criteria are at least one year since diagnosis, HbA1c >7%, >35 years, and living in a socioeconomically deprived neighbourhood. Exclusion criteria are GP objection to participation, severe psychiatric disorders, being unable to come to the intervention location independently, and planning to stay abroad for longer than six weeks during the intervention period.

Taking into account the prevalence of type 2 diabetes among ethnic minorities in lower SE groups in the Netherlands, we expect half of the study population to consist of ethnic Dutch patients and the other half to come from minority groups, in particular patients with Turkish, Moroccan, and Surinamese backgrounds.

Sample size calculation
The primary outcome measure is the decrease in HbA1c at 16 months. A decrease of 0.5% in the intervention group compared to the comparison group will be seen as a difference that is clinically relevant. This means that at a statistical significance of 5% and a power of 80%, we will need 92 participants in both the intervention and the comparison group. Bearing in mind a dropout rate of 40%, we will need to include 128 people in both the intervention group and the comparison group.
Measurements

**Primary and secondary outcome measures**
The primary outcome measures are the HbA1c levels of the participants and diabetes-related quality of life at 16 months after the start of the intervention.

The secondary outcome measures are:
- diabetes self-management (dietary habits, physical activity, monitoring of blood glucose, medication adherence, smoking, GP visits, body mass index (BMI))
- health-related outcome measures (blood pressure, heart rate, lipid profile, weight, waist and hip circumference)

Intermediate outcome measures are depression, attitude, knowledge, self-efficacy, coping skills, size and composition of participants’ social networks, social support, social influence, social engagement

**Data collection (procedure of effect evaluation and process evaluation)**
Data collection will take place at baseline (T0), after 3 months (T1), after 10 months (T2), and after 16 months (T3) for both the intervention group (PTWD) and the comparison group (KYS). At T1 we will only administer a short structured interview aimed to measure knowledge and DSM. At T0, T2, and T3 we will administer a structured interview and a physical examination. We will study the participants’ medical records at all data collection moments. The HbA1c levels of 128 patients who receive standard care will be collected from a large database owned by a GP collective in the Netherlands. See figure 1 for an overview of the measurements in this study.

**Structured interview**
Data on diabetes-related behaviour and psychosocial and intermediate outcome measures will be collected during a structured interview, which will be conducted by a trained interviewer. The questionnaire used in these interviews will be translated and back-translated into Turkish by two qualified independent translators and discussed with the researchers. Rather than Arabic, we expect the majority of our Moroccan participants to speak Berber or Moroccan Arabic. Both are spoken languages only. Therefore, the questionnaire will be translated into Berber and Moroccan Arabic during brainstorming sessions with three native speakers and the researchers in which they will reach consensus about the translation. The questionnaire will be written down phonetically. The female Moroccan and Turkish respondents and the interviewers will be matched according to gender. The interview will take place in the mother tongue of the participant.
As the target population has a low educational level, we searched for questionnaires that fit this level. Hence, we made a selection of existing questionnaires based on their reliability, validity, and inter-rater reliability among diverse ethnic populations and people in lower SE groups. We pretested the Diabetes Problem-Solving Inventory (DPSI), the Diabetes Social Support Questionnaire DSSQ-Friends Version and DSSQ-Family Version, the Theory of Planned Behaviour (TpB) Questionnaire, and the compilation of the Social Capital Question Bank (table 2), and adjusted them to optimally match our respondents’ ability to answer the questions. We removed...
items that our target population did not identify with (face validity) or that were irrelevant for this study. Furthermore, a professional adjusted the literacy level of the questionnaires to the lower educational level of our target population, and we adapted some items to make them more culturally sensitive for the different cultural groups in our study population. For example, in the DPSI we adjusted some of the vignettes to make them more appropriate for our different cultural groups. See Table 2 for an overview of the questionnaires we used.

**Physical examination**

The physical examination in the intervention (PTWD) and comparison group (KYS) will be administered at T0, T2, and T3, and will consist of a standardized measurement of weight, height, waist and hip circumference, blood pressure, and heart rate. An anthropometrical protocol will be used for these measurements. We will monitor the execution of this procedure.

**TABLE 2. | Overview of the questionnaires used in the DISC Study**

<table>
<thead>
<tr>
<th>Outcome measure</th>
<th>Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes-related quality of life</td>
<td>Diabetes-specific quality-of-life scale</td>
</tr>
<tr>
<td>Depression</td>
<td>4DKL (Four-Dimensional Compliant Questionnaire)</td>
</tr>
<tr>
<td>Knowledge</td>
<td>SKILLD (spoken knowledge in low literacy in diabetes scale)</td>
</tr>
<tr>
<td>Outcome expectations</td>
<td>OEDM-P (Outcome Expectations for Diabetes Self-Management-positive)</td>
</tr>
<tr>
<td></td>
<td>OEDM-N (Outcome Expectations for Diabetes Self-Management-negative)</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>Diabetes self-efficacy scale</td>
</tr>
<tr>
<td>Coping skills</td>
<td>DPSI</td>
</tr>
<tr>
<td>Social network</td>
<td>Compilation from the Social Capital Question Bank</td>
</tr>
<tr>
<td>Social support</td>
<td>DSSQ-Family Version</td>
</tr>
<tr>
<td></td>
<td>DSSQ-Friends Version</td>
</tr>
<tr>
<td>Social influence</td>
<td>TpB Questionnaire</td>
</tr>
</tbody>
</table>

**Blood and urine samples**

In the Netherlands, HbA1c levels and fasting plasma glucose of diabetic patients are measured every three months. An extensive analysis of blood and urine samples is performed at least once a year. For T0, T2, and T3, we will collect these data from the participants’ medical records. More specifically, we will collect:

- Fasting plasma glucose, HbA1c, total cholesterol, high-density lipoprotein (HDL) cholesterol, triglycerides, creatinine, and creatinine clearance, glomerular filtration rate calculated according to the Modification of Diet in Renal Disease Study (MDRD equation)
- Microalbuminuria
In addition, we will use medical records to collect information on the participants’ medication use and diabetes-related complications: retinopathy, cataract, kidney failure, microalbuminuria, myocardial infarction, angina pectoris, transient ischaemic attack (TIA), cerebrovascular accident (CVA), claudicatio intermittens, diabetic ulcers, amputation, polyneuropathy, and sensitivity problems in the feet.

Qualitative study
We will perform a qualitative study to gain in-depth understanding of the key mechanisms of PTWD: changes in the psychosocial mechanisms in the immediate social environments of the participants. We will administer semi-structured qualitative interviews with PTWD and KYS participants. Topics will include overall experiences with the intervention, perceived changes in the immediate social environment (psychosocial mechanisms and social support), and perceived benefits of the intervention regarding coping skills and DSM.

Process evaluation
The aim of the process evaluation is to gather in-depth information regarding the fidelity and feasibility of PTWD and KYS. Data collection will take place during the entire intervention period. We will study the journals and files of the group leaders, in which they will record the intervention’s implementation and progress. In addition, we will regularly observe group meetings, and we will administer a questionnaire and semi-structured in-depth interviews to the group leaders and the participants.

Cost-effectiveness
For both PTWD and KYS, we will calculate the organizational costs (e.g. expenses incurred during the intervention, such as hiring group leaders and locations and developing intervention materials), non-medical costs (e.g. expenses incurred by participants because of their participation in the intervention, such as travel expenses), and medical costs (e.g. medical expenses incurred by participants during the intervention, such as the medication they used and visits to their GPs). We will also compare these costs with an estimation of the expenses incurred by the patients in the standard care group.

STATISTICAL ANALYSES

Assessment of effect
Descriptive statistics will be applied to describe the study population at baseline. To determine the effect of the intervention on HbA1c levels and diabetes-related qual-
ity of life and to follow individual change over time, we will use generalized linear mixed models. Potential confounders and effect modifiers (e.g. depression, gender, and ethnicity) will be investigated. We will further examine predictors (including intervention-related predictors) of a decrease in HbA1c levels and an increase in diabetes-related quality of life. If necessary, we will use propensity scores to estimate the effects. The level of significance is set at p < 0.05.

The analyses of the qualitative data (semi-structured in-depth interviews with the participants) will be done by two researchers using MAXQDA 10, a programme for qualitative data analysis. We will construct an initial conceptual framework based on the theoretical assumptions of the intervention. The data will be coded according to this framework using an inductive approach to also include other aspects related to the identified themes and concepts. Next, we will sort and synthesize the data using thematic charting and further analyse the data by detecting patterns and developing explanations.

**Assessment of process**
All qualitative data (journals and files of the group leaders, semi-structured in-depth interviews) will be analysed with MAXQDA according to the principles of content analysis. The quantitative (semi-structured questionnaires) data will be analysed with SPSS using descriptive statistics.

**Cost-effectiveness**
The costs of the interventions will be described and compared to the quality-of-life outcome measures.

**DISCUSSION**
Growing evidence suggests that in addition to social support, other psychosocial mechanisms in the immediate social environments of diabetic patients such as social influences and social engagement have a major influence on DSM as well. Diabetic patients in lower SE groups in particular seem to be confronted with strong psychosocial mechanisms that have an adverse effect on their DSM and seem to experience more difficulties in coping with these mechanisms. Therefore, to improve DSM among these groups it seems necessary to target all psychosocial mechanisms in the immediate social environment that impact their DSM: social support, social influence, and social engagement.
PTWD is, to our knowledge, the first culturally sensitive social network intervention targeted to lower SE groups that aims to stimulate the long-term social support of peers and the immediate social environment, and to target existing psychosocial mechanisms through which the immediate social environment negatively influences DSM. The DISC Study evaluates the effectiveness of PTWD.

A limitation of this study might be that blinding the GPs during the study was impossible. Another limitation that might bias the comparability of the groups is that it was impossible to randomize the intervention and comparison groups due to characteristics of the intervention. We think that the chance of selection bias will be small, because both the intervention and the comparison groups will be invited to a lifestyle intervention. We will record all reasons for participation and non-participation among our respondents, which will enable us to assess any selection bias. In addition, we will control for differences between the groups at baseline and take these differences into account during the analyses.

The present study will be strengthened by the use of data triangulation. We will use a wide variety of sources of information such as questionnaires, semi-structured qualitative interviews, medical records, physical examinations, and the journals and files of the group leaders. This will increase the validity of this study. Moreover, the qualitative semi-structured interviews will reveal in-depth information about lower SE groups that is lacking to date.

This study will provide insights into how to enable people with diabetes in lower SE groups to optimally manage their diabetes by intervening in the psychosocial mechanisms in the social environment that negatively impact their DSM: social support, social influences, and social engagement. If PTWD is effective in lowering the HbA1c levels of the participants and improving their diabetes-related quality of life, further implementation will be considered. PTWD could be implemented in the context of a GP practice, where it could contribute to more efficient diabetes care for diabetic patients in lower SE groups.

LIST OF ABBREVIATIONS

- DISC (Diabetes in Social Context) Study
- socioeconomic (SE)
- diabetes self-management (DSM)
- Powerful together with diabetes (PTWD)
The DISC (Diabetes in Social Context) Study

- Know your Sugar (KYS)
- Dutch National Institute for Health Promotion and Disease Prevention (NIGZ)
- general practitioner (GP)
- Diabetes Problem-Solving Interview (DPSI)
- Diabetes Social Support Questionnaire (DSSQ)
- Theory of Planned Behaviour (TpB)
- body mass index (BMI)
- haemoglobin A1C (HbA1c)
- significant others (SO)
- Academic Medical Center (AMC)
- transient ischaemic attack (TIA)
- cerebrovascular accident (CVA)

COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHORS’ CONTRIBUTION

CV coordinates the study, and developed the intervention, constructed the design, and drafted the manuscript. DG developed the outline of the intervention and the intervention materials. VN and KS developed the study, constructed the design, and revised the manuscript. PJMU, BJCM, and GN participated in the design of the study and revised the manuscript. All authors read and approved the final manuscript.

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REFERENCES


## ADDENDUM

### ADDENDUM 1. Summary of behavioural goals, determinants addressed, and strategies used in PTWD phase 1

<table>
<thead>
<tr>
<th>Phase 1 (1-3 months)</th>
<th>Behavioural goals</th>
<th>Main determinants addressed</th>
<th>Strategies (programme components)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Knowing what diabetes is and how to optimally manage it (monitoring of blood glucose, medication adherence, diet, physical activity)</td>
<td>Knowledge</td>
<td>Interactive diabetes quiz Repetition of information</td>
</tr>
<tr>
<td></td>
<td>Feeling that DSM is necessary and beneficial</td>
<td>Outcome expectations</td>
<td>Positive role-model stories Shared positive experiences from group members (vicarious reinforcement) Group discussions</td>
</tr>
<tr>
<td></td>
<td>Believing that you are the one who should and can influence the course of your diabetes</td>
<td>Moral norms</td>
<td>Positive role-model stories Shared positive experiences from group members (vicarious reinforcement) Group discussions</td>
</tr>
<tr>
<td></td>
<td>Asking for social support in having and dealing with diabetes</td>
<td>Self-efficacy</td>
<td>Letter of the week Rehearsal situations Real-life ‘excursions’</td>
</tr>
<tr>
<td></td>
<td>Being aware of the effect psychosocial mechanisms have on your DSM and being able to deal with these mechanisms</td>
<td>Social support</td>
<td>Interactive games (self-affirmation) Stimulating the exchange of advice Positive role models focused on social support Group meetings for significant others</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Skills</td>
<td>Letter of the week Rehearsal situations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social influence</td>
<td>Role-model stories Letters of the week Rehearsal situations Group discussions</td>
</tr>
</tbody>
</table>
### ADDENDUM 1. | Summary of behavioural goals, determinants addressed, and strategies used in PTWD phase 1 (continued)

<table>
<thead>
<tr>
<th>Behavioural goals</th>
<th>Main determinants addressed</th>
<th>Strategies (programme components)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Selection of behavioural goals regarding social support in Phase 1</strong></td>
<td>The participants trust each other and share experiences with each other</td>
<td>Setting rules for the disclosure of information in the group (no gossiping)</td>
</tr>
<tr>
<td></td>
<td>Outcome expectations</td>
<td>Interactive games and energizers to build trust: giving each other compliments, weaving the web of life, solving puzzles together, sharing positive news at home with each other</td>
</tr>
<tr>
<td></td>
<td>Perceived norms</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Moral norms</td>
<td></td>
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<tr>
<td></td>
<td>Self-efficacy and skills</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social influence</td>
<td></td>
</tr>
<tr>
<td>Participants listen carefully to each other and give each other positive feedback</td>
<td>Communication skills (giving positive feedback)</td>
<td>Focus of group leader on listening and positive feedback</td>
</tr>
<tr>
<td></td>
<td>Outcome expectations</td>
<td>Practice with guided feedback</td>
</tr>
<tr>
<td></td>
<td>Perceived norms</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Moral norms</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Self-efficacy and skills</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Social influence</td>
<td></td>
</tr>
</tbody>
</table>

DSM: diabetes self-management

### ADDENDUM 2. | Summary of behavioural goals, determinants addressed, and strategies used in PTWD phase 2

<table>
<thead>
<tr>
<th>Behavioural goals</th>
<th>Main determinants addressed</th>
<th>Strategies (programme components)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phase 2</strong> (4-12 months)</td>
<td>Identifying problems and barriers to your DSM (monitoring of blood glucose, medication adherence, diet, physical activity)</td>
<td>Diaries</td>
</tr>
<tr>
<td></td>
<td>Awareness of barriers</td>
<td>Role-model stories</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Exchange of experiences</td>
</tr>
<tr>
<td>Being able to come up with possible solutions for these barriers</td>
<td>Problem-solving skills</td>
<td>Participatory problem-solving</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rehearsal situations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Homework assignments followed by feedback</td>
</tr>
<tr>
<td></td>
<td>Self-efficacy</td>
<td>Rehearsal situations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Homework assignments followed by feedback</td>
</tr>
</tbody>
</table>
### ADDENDUM 2. | Summary of behavioural goals, determinants addressed, and strategies used in PTWD phase 2 (continued)

<table>
<thead>
<tr>
<th>Behavioural goals</th>
<th>Main determinants addressed</th>
<th>Strategies (programme components)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actively involving family and/or friends when overcoming these barriers</td>
<td>Communication strategies, Self-efficacy, Asking for and receiving social support, Handling social influence on DSM</td>
<td>Role-model stories focused on these topics, Rehearsal situations focused on these topics, Homework assignment focused on these topics, Encouraging the participants to see each other in between the group meetings and undertake DSM activities (e.g. exercising) together, Social network meetings with significant others</td>
</tr>
<tr>
<td>Being able to evaluate and improve the strategies chosen to overcome these barriers</td>
<td>Self-efficacy, Problem-solving skills</td>
<td>Rehearsal situations, Homework assignments followed by feedback, Participatory problem-solving, Rehearsal situations, Homework assignments followed by feedback</td>
</tr>
</tbody>
</table>

**Selection of behavioural goals regarding social support in Phase 2**

- The participants feel like a team
  - Outcome expectations, Perceived norms, Moral norms, Collective self-efficacy and skills, Social support, Social influence, Social engagement
  - Focus of group leader on togetherness and supporting each other, Participatory problem-solving, Team-building energizers

- The participants continue to support each other outside of the group meetings
  - Outcome expectations, Perceived norms, Moral norms, Collective self-efficacy and skills, Social support, Social influence
  - Focus of group leader on the continued existence of the group, Guided practice with feedback, Making appointments with other group members

DSM: diabetes self-management
### ADDENDUM 3. | Summary of behavioural goals, determinants addressed, and strategies used in the meetings for significant others of PTWD

<table>
<thead>
<tr>
<th>Behavioural goals</th>
<th>Main determinants addressed</th>
<th>Strategies (programme components)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SOs know what diabetes is and how to optimally manage it (monitoring of blood glucose, medication adherence, diet, physical activity)</td>
<td>Knowledge</td>
<td>Interactive diabetes quiz</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Repetition of information</td>
</tr>
<tr>
<td>SOs believe that the DSM of the diabetic patient is a shared responsibility</td>
<td>Moral norms and outcome expectations</td>
<td>Positive role-model stories</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Shared positive experiences of other SOs (vicarious reinforcement)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Group discussions</td>
</tr>
<tr>
<td>SOs regularly inquire how things are going with the management of diabetes (monitoring of blood glucose, medication adherence, diet, physical activity)</td>
<td>Social influences Perceived norms and social expectations</td>
<td>Role-model stories</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Letter of the week</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rehearsal situations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Group discussions</td>
</tr>
<tr>
<td></td>
<td>Moral norms and outcome expectations</td>
<td>Positive role-model stories</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Shared positive experiences of other SOs (vicarious reinforcement)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Group discussions</td>
</tr>
<tr>
<td></td>
<td>Self-efficacy and (communication) skills</td>
<td>Letter of the week</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rehearsal situations</td>
</tr>
<tr>
<td>If the DSM is going well, the SO gives compliments to the diabetic patient</td>
<td>Outcome expectations</td>
<td>Positive role-model stories</td>
</tr>
<tr>
<td>If the diabetic patient is experiencing difficulties with his/her DSM, the SO gives positive feedback</td>
<td>Self-efficacy and (communication) skills</td>
<td>Shared positive experiences from group members (vicarious reinforcement)</td>
</tr>
<tr>
<td></td>
<td>Perceived norms and social expectations</td>
<td>Group discussions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Letter of the week</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rehearsal situations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Group discussions</td>
</tr>
</tbody>
</table>

DSM: diabetes self-management  
SO: significant other
### ADDENDUM 4. Summary of behavioural goals, determinants addressed, and strategies used in the social network meetings of PTWD

<table>
<thead>
<tr>
<th>Behavioural goals</th>
<th>Determinants addressed</th>
<th>Strategies (programme components)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SO and diabetic patient together identify the diabetic patient’s obstacles for DSM (monitoring of blood glucose, medication adherence, diet, physical activity)</td>
<td>Awareness of barriers</td>
<td>Exchange of experiences and thoughts on DSM</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Discussion of the diabetic patient’s personal action plan</td>
</tr>
<tr>
<td>SO and diabetic patient together make a plan to overcome these obstacles</td>
<td>Problem-solving skills</td>
<td>Group discussion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Participatory problem-solving</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Guided feedback from group leader</td>
</tr>
<tr>
<td>SO and diabetic patient execute the plan they made together</td>
<td>Collective self-efficacy</td>
<td>Homework assignment followed by feedback</td>
</tr>
<tr>
<td>SO and diabetic patient evaluate the plan and make adjustments if necessary</td>
<td>Collective self-efficacy</td>
<td>Giving each other positive feedback</td>
</tr>
<tr>
<td></td>
<td>Problem-solving skills</td>
<td>Guided feedback from group leader</td>
</tr>
</tbody>
</table>

DSM: diabetes self-management  
SO: significant other
The impact of a social network based intervention promoting diabetes self-management in socioeconomically deprived patients: a qualitative evaluation of the intervention strategies

C. Vissenberg
K. Stronks
G. Nijpels
P. J. M. Uitewaal
B. J. C. Middelkoop
M. J. E. Kohinor
M. A. Hartman
V. Nierkens

Based on:


Chapter 4

ABSTRACT

Objective

There is a need for effective interventions that improve diabetes self-management (DSM) among socioeconomically deprived patients with type 2 diabetes. The group-based intervention Powerful Together with Diabetes (PTWD) aimed to increase social support for DSM and decrease social influences hindering DSM (e.g. peer pressure, social norms) in patients living in socioeconomically deprived neighbourhoods. Through a qualitative process evaluation, this paper aims to study whether this intervention changed social support and social influences, and which elements of the intervention contributed to this.

Methods

The intervention group (IG) was compared to a standard group-based educational intervention (control group, CG). Twenty-seven qualitative in-depth interviews with participants (multi-ethnic sample) and 24 interviews with group leaders were conducted. Interviews were coded and analysed using MAQDA according to framework analysis.

Results

Patients in the IG experienced more emotional support from group members and more instrumental and appraisal support from relatives than those in the CG. Also, they were better able to recognize and cope with influences that hinder their DSM, exhibited more positive norms towards DSM and increased their priority regarding DSM and their adherence. Finally, the engagement in DSM by relatives of participants increased. Creating trust between group members, skills training, practising together, and actively involving relatives through action plans contributed to these changes.

Conclusions

A group-based intervention aimed at creating trust, practising together, and involving relatives has the potential to increase social support and diminish social influences hindering DSM in socioeconomically deprived diabetes patients. Promising elements of the intervention were skills training and providing feedback using role-playing exercises in group sessions with patients, as well as the involvement of patients’ significant others in self-management tasks, and actively involving them in
making an action plan for self-management. These positive results justify the value of further evaluating the effectiveness of this intervention in a larger sample.

BACKGROUND

People in lower socioeconomic groups are not only disproportionately affected by type 2 diabetes, they also have more diabetes-related complications and higher diabetes-related mortality compared to patients in higher socioeconomic groups \(^1{-3}\). A poorer glycaemic control, related to less adequate self-management behaviour, partly accounts for these increased risks \(^4\). Properly managing type 2 diabetes requires a schedule of extensive self-management behaviours. These include frequent monitoring of blood glucose levels, balancing insulin dosages with food intake and physical activity, and prevention or treatment of hypoglycaemia. Complying with and maintaining such complex health regimens seems to be challenging, especially for socioeconomically deprived patients \(^5{-7}\).

There is thus a need for effective interventions that improve glycaemic control among socioeconomically deprived patients with type 2 diabetes. Interventions that target social influences affecting self-management behaviour, such as social support, might be promising. Social interactions with friends and family members have a major impact on self-management. Social support, the aid and assistance exchanged through social relationships and interpersonal transactions, can positively influence self-management, but significant others can also hinder self-management by interfering with or paying too much attention to self-management \(^8,9\). Socioeconomically deprived patients seem to have less access to supportive social networks, to generally have fewer sources of social support in their social environments and to receive less social support, which is needed for adherence \(^10{-12}\). In addition, they are often confronted with social influences from their immediate social environments that hinder self-management (e.g. peer pressure, specific cultural beliefs and expectations, and fewer positive role models) \(^13,14\).

A few studies indicate the effectiveness of a social network based intervention on diabetes control \(^15,16\). Little is known, however, about intermediate variables such as social support or social influences and the intervention strategies by which these effects can be established. In other words, which strategies should be used in social network based interventions to actually stimulate social support in the immediate social environment and to diminish hindering social influences on self-manage-
ment, especially among socioeconomically deprived patients? This knowledge is imperative to further develop this type of interventions.

Therefore we developed a social network based intervention (Powerful Together with Diabetes) that aimed to stimulate social support for self-management and to diminish hindering social influences on self-management among socioeconomically deprived patients. The intervention consisted of a series of 24 meetings in which the patients as a group learned about diabetes and practiced these newly learned behaviours. At the same time their significant others received an intervention as well aimed at increasing knowledge and supporting someone with diabetes. Home visits were also conducted to make a shared action plan for the patient and his/her significant others.

The aim of this paper is to determine how the intervention worked. More specifically, we studied which changes in social support and social influences were experienced by participants and which of the employed intervention strategies were effective in increasing social support for self-management and diminishing social influences hindering self-management. A qualitative approach was used to explore and understand these strategies.

METHODS

The study reported here is part of the DISC study, the design of that study is described elsewhere. An experimental non randomized design with an intervention and a control group was used. For the intervention to be successful, it was important that the participants lived near each other which made randomization impossible. The intervention was compared to standard group based diabetes education to be able to determine the additive value of actively intervening on social support, social influences and the immediate social environment of patients at the same time. The intervention group received Powerful Together with Diabetes, the control group received Know Your Sugar (see figure 1). The quasi-experimental trial was accompanied by a process evaluation that aimed to explore the mechanisms that underlied the effect of the intervention: why did it work? The DISC study has been approved by the Medical Ethics Committee of the Academic Medical Center (AMC) in Amsterdam, the Netherlands.

The primary outcome measure of the trial were HbA1c and quality of life. To show the effect of the intervention, power calculations showed that 128 participants had
A qualitative evaluation of the intervention strategies

Multiple recruitment problems were encountered such as difficulties recruiting GPs due to busy works schedules, incomplete or outdated contact information in the GPs’ records, and eligible participants not answering their phones. Also, eligible patients indicated that they were too busy, had to look after relatives, did not want to improve their self-management or did not want to participate in a group. Therefore at the beginning of the intervention, we were only able to recruit half of the required numbers. As a consequence, the effect of the intervention on quality of life and HbA1c could not be studied. This paper reports on the data of the process evaluation, regarding the intervention mechanisms.

Patients who met the following criteria were selected from the patient records of general practitioners (GPs): having type 2 diabetes, diagnosed for at least one year, older than 35, glycated haemoglobin (HbA1c) higher than 53 mmol/mol (7.0%), and living in a socioeconomically deprived neighbourhood according to an official ranking of the Dutch government. These neighbourhoods are characterized by living conditions that are of lower quality than those in other neighbourhoods due to a cumulation of problems. These problems consist of high unemployment rates, low income, high criminality, degradation, feelings of unsafety, a lack of relevant social networks and social contacts. Patients with severe psychiatric disorders, and those who were unable to come to the intervention location, or planned to stay abroad for longer than six weeks were excluded. The intervention and control groups were matched on gender, ethnicity, and organization of diabetes care.

Both Powerful Together with Diabetes and Know Your Sugar were group-based interventions, with 7-10 participants per group. Ten intervention groups with a total of 69 patients participated in Powerful Together with Diabetes. Nine control groups with a total of 62 patients participated in Know Your Sugar (see table 1).
TABLE 1. Characteristics of respondents in the DISC study and the process evaluation

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Quasi-experimental trial</th>
<th>Qualitative process evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intervention group (n = 69)</td>
<td>Control group (n = 62)</td>
</tr>
<tr>
<td>Age (SD)</td>
<td>61.15 (10.4)</td>
<td>62.3 (9.9)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>66.1%</td>
<td>69.8%</td>
</tr>
<tr>
<td>Total household income per month</td>
<td></td>
<td></td>
</tr>
<tr>
<td>€454–€1,270</td>
<td>34.8%</td>
<td>46.8%</td>
</tr>
<tr>
<td>€1,270–€1,906</td>
<td>30.4%</td>
<td>25.8%</td>
</tr>
<tr>
<td>More than €1,906</td>
<td>10%</td>
<td>9.7%</td>
</tr>
<tr>
<td>Would rather not say</td>
<td>24.6%</td>
<td>17.7%</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dutch</td>
<td>40.6%</td>
<td>27.4%</td>
</tr>
<tr>
<td>Surinamese</td>
<td>11.6%</td>
<td>32.3%</td>
</tr>
<tr>
<td>Turkish</td>
<td>10.1%</td>
<td>16.1%</td>
</tr>
<tr>
<td>Moroccan</td>
<td>15.9%</td>
<td>6.5%</td>
</tr>
<tr>
<td>Other</td>
<td>8.7%</td>
<td>9.7%</td>
</tr>
<tr>
<td>Missing</td>
<td>13%</td>
<td>8.1%</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No formal education/primary education</td>
<td>50%</td>
<td>52.6%</td>
</tr>
<tr>
<td>Lower secondary vocational education (LBO) or preparatory secondary vocational education (VMBO)</td>
<td>20.3%</td>
<td>21.1%</td>
</tr>
<tr>
<td>How would you describe the state of your diabetes?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very good</td>
<td>5%</td>
<td>4.4%</td>
</tr>
<tr>
<td>Good</td>
<td>36.7%</td>
<td>40.4%</td>
</tr>
<tr>
<td>Okay</td>
<td>40.0%</td>
<td>44.4%</td>
</tr>
<tr>
<td>Poor</td>
<td>13.3%</td>
<td>11.1%</td>
</tr>
<tr>
<td>Very poor</td>
<td>5%</td>
<td>0%</td>
</tr>
<tr>
<td>HbA1c at baseline mmol/mol (SD)</td>
<td>62 mmol/mol 7.80% (1.1)</td>
<td>63 mmol/mol 7.95% (1.7)</td>
</tr>
<tr>
<td>Duration of diabetes in years (SD)</td>
<td>8.36 (8.0)</td>
<td>11.65 (10.2)</td>
</tr>
</tbody>
</table>

SD: standard deviation

THE INTERVENTION (POWERFUL TOGETHER WITH DIABETES) AND CONTROL (KNOW YOUR SUGAR) GROUPS

In short, Powerful Together with Diabetes lasted 10 months and consisted of 24 group meetings for the participants, 6 sessions for their significant others (relatives or friends), and two social network therapy sessions at home in which both participants and their significant others were present\footnote{17}. Significant others were selected and invited by the participants with a maximum of two persons per participant. The participants were asked to invite someone who was important with regard to their
diabetes self-management. The intervention objectives were to get the participants to support and positively influence each other to better manage their diabetes (e.g. positive peer pressure), to effectively handle social influences that hinder self-management (e.g. relatives who keep offering them sweets), and to increase the engagement and support of relatives and friends in self-management (e.g. by asking them to exercise together). Table 2 provides an overview of the general objectives regarding these determinants, the more specific sub-goals that emerged from these objectives, and their matching intervention strategies. Powerful Together with Diabetes was realized in 10 groups from August 2010 through December 2011. All groups finished both phases of the intervention, except for the Moroccan male group which ended after part 1 due to a lack of sufficient motivation.

Know your Sugar lasted six weeks and consisted of six group meetings for the participants, and was based on standard diabetes education in the Netherlands. In the Netherlands, standard education for patients with type 2 diabetes consists of information and education about type 2 diabetes and self-management from the GP, GP assistant or diabetes nurse. Further, patients are advised to quit smoking, to regularly exercise, to lose weight when having a BMI > 25 kg/m², and to eat healthy for which they are referred to a dietician¹⁹. It aimed to provide the participants with the information they needed to manage their diabetes. Though it provided the participants with the opportunity to get to know other patients, to influence each other and to exchange social support, it did not specifically target these determinants or intervene in the immediate social environments of participants. Know your Sugar was realized in 9 groups from January 2011 through November 2011. All groups finished the intervention; however, the Moroccan male group did not start due to a lack of interest among the potential participants.
<table>
<thead>
<tr>
<th>General objective</th>
<th>Sub-goals</th>
<th>Intervention strategies</th>
</tr>
</thead>
</table>
| **1.** Extending participants’ diabetes-related social networks, facilitating the exchange of social support and positive social influences with group members. | - Participants positively influence each other (role models, positive peer pressure, positive group norms).  
- Participants encourage and support each other in adhering to their self-management during the intervention, and continue to support each other after the intervention has ended (advice, helping each other).  
- Participants continue to see each other after the intervention, and continue to do DSM-related activities together (e.g. exercising). | **Group meetings for patients with diabetes, Phases 1 and 2**  
- Participants took part in interactive games and energizers (short breaks during the intervention in order to keep the participants motivated and concentrated during the rest of the program. Energizers often consisted of short exercises aimed at group bonding, e.g. throwing a balloon back and forth while giving each other compliments)  
- In which they had to team up with someone or form alliances. They were encouraged to open up to each other through these games and energizers.  
- Participants were regularly invited to talk about their self-management problems and to ask group members for advice. To do this, the group members learned skills for giving constructive feedback.  
- In small subgroups, participants did assignments in which they had to help each other (e.g. adjusting recipes together) to get used to giving and receiving social support.  
- Participants were encouraged to phone and/or meet up with each other outside of the group meetings.  
**Group meetings for patients with diabetes, Phase 2**  
- Periodic (first two weekly, then monthly) meetings were held. Participants were encouraged to continue seeing each other in between group meetings without the group leader. |
<table>
<thead>
<tr>
<th>General objective</th>
<th>Sub-goals</th>
<th>Intervention strategies</th>
</tr>
</thead>
</table>
| 2. Increasing participants' abilities to handle social influences that hinder their self-management, such as norms, peer pressure, and temptations. | - Participants critically evaluate the impact significant others have on their DSM.  
- Participants are better able to deal with social influences that hinder their self-management, such as peer pressure (e.g. pressure to eat unhealthy foods or to overeat, or negative feedback when exercising or taking medications). | **Group meetings for patients with diabetes, Phase 1**  
- Group discussions were held about social situations in which managing diabetes is difficult (in response to a DVD, a letter of the week, and of their own accord).  
- Participant practised these strategies with group members during role-playing exercises.  
**Group meetings for patients with diabetes, Phase 2**  
- An action plan was drawn up in which social influences and dealing with social influences played an important part (group meetings). Together with other group members, the person with diabetes came up with strategies and solutions to overcome these difficulties. |
### TABLE 2. Overview of sub-goals and strategies of Powerful Together with Diabetes (continued)

<table>
<thead>
<tr>
<th>General objective</th>
<th>Sub-goals</th>
<th>Intervention strategies</th>
</tr>
</thead>
</table>
| **3. Increasing the engagement and support of the participants' significant others in self-management.** | - Participants ask significant others for support.  
- Participants indicate that their significant others are more involved in their self-management (providing more support or more enabling social influences).  
- Participants experience more enabling social influences.  
- Participants experience fewer social influences from their significant others that hinder their self-management. | **Group meetings for patients with diabetes, Phase 1**  
- Participants were encouraged to tell their significant others they have diabetes (if they did not know).  
- Participants were encouraged to tell their significant others about the negative social influences and barriers they face (social network therapy).  
**Social network therapy session, Phase 2**  
- Participants discussed solutions and strategies with their significant others to deal with negative social influences on self-management.  
- Together with their significant others, participants agreed on an action plan in which the significant others play an active role in their self-management. In this action plan, the participant and his/her significant other(s) described the problem they would be working on and barriers and facilitators to overcome this problem. Finally they agreed on some concrete appointments with each other to overcome this problem.  
**Group meetings for significant others, Phases 1 and 2**  
- Significant others learned more about diabetes and the important role they play in the self-management of the patient with diabetes.  
- To change their norms regarding self-management tasks, the significant others critically evaluated their own lifestyles through interactive games.  
- Significant others did interactive assignments in which they distinguished helpful and non-helpful behaviour with regard to self-management.  
- Group discussions were held about ways to better facilitate the self-management of their relative with diabetes.  
- Significant others learned ways to ask about their relative’s self-management in a friendly, supportive way (group meetings for significant others). |
Both interventions were guided by different group leaders who were matched with the participants based on ethnicity and gender. The group leaders were recruited through an advertisement and selected based on their prior experience with group-based education. The group leaders of the Dutch groups were diabetes nurses, GP assistants and physician assistants. The group leaders of the Moroccan, Turkish and Surinamese groups were lay health educators. Prior to the intervention, the group leaders of the intervention group received an eight-hour training and the group leaders of the control group a two-hour training. Both trainings focused on the implementation of the intervention. They differed in length due to the length (10 months) and complexity of Powerful Together with Diabetes.

**RECRUITMENT AND SAMPLING**

Qualitative in-depth semi-structured interviews with participants from the intervention and control groups and their group leaders were conducted. The aim was to interview two participants per group. Because this is a hard to reach study population, the group leaders were asked to select and invite the respondents. We asked them to invite two participants that had been attending the intervention regularly and who had significant others that also participated in the intervention.

In total, 27 participants agreed to be interviewed: 17 participants from 8 intervention groups (11 Dutch, 2 Turkish women, 2 Moroccan men, and 2 Surinamese) and 10 participants from 6 control groups (7 Dutch, 2 Moroccan women, and 1 Surinamese). 11 participants refused to participate. They lacked the time to participate, were on holiday or felt like they had spent enough time on the study procedures (filling out questionnaires and the physical exam). These respondents broadly reflected the wider trial population in terms of age, gender, duration of diabetes, and glycaemic control (see Table 1). Response among group leaders (n = 15) was 100%.

**DATA COLLECTION**

The interviews with the participants (n = 27) lasted 40–60 minutes. The interviews with the group leaders lasted approximately 60–90 minutes. The intervention group leaders (n = 9) were interviewed twice (once during and once after the intervention) to prevent possible memory bias caused by the length of the intervention. All control group leaders (n = 6) were interviewed once (right after the intervention ended).
The respondents were interviewed by themselves in their first language at the respondents’ homes, or in a community centre. The interviews were conducted by C.V. and M.J.E.K. with the help of an interpreter (Turkish interviews) or a Moroccan interviewer who had received training prior to the data collection. The Moroccan interviewer met the respondents before during other study procedures. The respondents met C.V. and M.J.E.K. during the observations in the intervention. Also, C.V. and M.J.E.K. had regular contact with the group leaders during the implementation of the intervention. The interviewers introduced themselves with little background information and emphasized they had no competing interest while conducting the interviews. They focused their introduction on wanting to evaluate the intervention and wanting to hear all (both positive and negative) experiences with the intervention. The interviews were audiotaped and transcribed with the respondents’ consent. A topic guide was used during all of the interviews. For the participants, topics included experiences with the intervention, changes made in self-management, changes in support for and social influences on self-management, and how they experienced contacts with group members (addendum 1). For the group leaders, topics included experiences with the intervention, changes in participants’ self-management that they observed and heard from participants, barriers and facilitators, and points for improvement (addendum 2). After the interview field notes were made to remember the setting and the impression the respondent made on the researcher.

ANALYSIS

Three of the researchers analysed the interviews with the participants using MAXQDA. The initial coding was done by C.V., and checked by M.J.E.K. Consensus was reached by discussion. To preclude bias, their coding was randomly checked by a third researcher, M.A.H. (who was blinded for intervention or control group).

We constructed an initial conceptual framework based on the theoretical assumptions of the intervention. The data were coded according to this framework. To determine whether the intervention’s general objectives had been achieved, the interviews were searched for patterns regarding the sub-goals. When a pattern was found in one group, the researchers tried to find the same pattern in the other group as well. When patterns were found only in the intervention group, they were considered to be an indication that these patterns, or differences in patterns, had been caused by the intervention Powerful Together with Diabetes.
The interviews with the group leaders were used to check and consolidate the findings that emerged from the interviews with participants through data triangulation. After determining relevant patterns in the interviews with participants, we checked if these findings could be confirmed by the interviews with group leaders.

**RESULTS**

The respondents were predominantly female, aged around 60 years who had diabetes for 8-10 years and regarded the state of their diabetes as okay- very good (Table 1). Around 30% had no education, or primary education only. Two third had a total house income of less than €1906 per month. None of the respondents in the qualitative study considered the state of their diabetes to be poor or very poor, despite their actual HbA1c levels, which indicate that their average blood glucose levels had not been well controlled for the last weeks. In general the respondents of the qualitative study reflected the entire study population, but had a slightly higher income, education, and better self-rated diabetes-related health compared to the general study population. The significant others of these respondents that participated in the intervention were predominantly husbands or wives (n = 13). Sometimes these respondents invited a niece, an in-law, a daughter or a neighbour (n = 5) to the intervention as well besides their spouses. Two respondents did not have any significant others that participated in the interventions and of two respondents only their daughters participated.

The experienced changes in social support and social influences are described according to the general objectives of the intervention in table 3. The intervention strategies attributed to these changes are described in table 4.

1. **Extending participants’ diabetes-related social networks, facilitating the exchange of social support and positive social influences (General objective 1).**

Respondents in both the intervention and control groups indicated that before the intervention, they did not talk about their diabetes with people other than their immediate social environment (spouse, children, and very close friends). The reasons given for not disclosing this, even to other people with diabetes, were fear that people would only ask about their diabetes (‘becoming diabetes’), standing out at social events, and not wanting to discuss it with strangers. Because only a few people knew about their diabetes, they could not exchange experiences with other people with diabetes and received little diabetes related support.
<table>
<thead>
<tr>
<th>General objective</th>
<th>Patterns found in intervention group after participating in the intervention (n = 17)</th>
<th>Patterns found in control group after participating in the intervention (n = 10)</th>
</tr>
</thead>
</table>
| **1. Extending participants’ diabetes-related social networks, facilitating the exchange of social support and positive social influences.** | **During the intervention:**
1. Change in norms towards self-management behaviours because of social influences from group members (*)
2. Group members positively influenced each other by encouraging a healthy lifestyle and the use of medications (*)
3. Participants exchanged stories and experiences and felt comforted by each other – emotional support (*)
4. Participants exchanged advice and experiences about nutrition, exercise, taking medications, and low and high blood glucose – informational support (*)
5. Participants felt better because group members were worse off than they were (*)

**After the intervention:**
6. Visiting each other (*)
7. Exercising together (*)
8. Getting together as a group (*)
9. Phoning each other (*)
10. Running into each other on the street (*) | **During the intervention:**
Not observed
during the intervention.
Not observed
Not observed
Participants exchanged experiences and felt comforted by each other – emotional support (*)
Participants received lots of information and solutions from group members about insulin – informational support (*)
Participants felt better because group members were worse off than they were (*)
Not observed
Not observed
Not observed
Phoning each other (*)
Running into each other on the street (*) |
<table>
<thead>
<tr>
<th>General objective</th>
<th>Patterns found in intervention group after participating in the intervention (n = 17)</th>
<th>Patterns found in control group after participating in the intervention (n = 10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Increasing participants’ abilities to handle social influences that hinder their self-management, such as norms, peer pressure and temptations.</td>
<td>1. Naming hindrances to self-management in their immediate social environments (e.g., lack of support, responsibilities towards relatives) and knowing these are barriers (13 respondents from 4 Dutch, 1 Surinamese, 1 Turkish and 1 Moroccan men group)</td>
<td>Naming hindrances to self-management in their immediate social environments (e.g., family responsibilities) and knowing these are barriers (1 respondents, group 9), of these: not knowing these are barriers (3 respondents from 2 Dutch groups)</td>
</tr>
<tr>
<td></td>
<td>2. Naming facilitators to self-management in their immediate social environments of their own accord, e.g. change in significant others’ behaviour (6 respondents from 3 Dutch, 1 Surinamese and 1 Moroccan men group)</td>
<td>Not observed</td>
</tr>
<tr>
<td></td>
<td>3. Better able to resist food temptations at home or at parties or more capable of saying no when pressured to eat too much or to eat unhealthy foods (7 respondents, from 4 Dutch, 1 Surinamese and 1 Turkish women group)</td>
<td>Being more serious about refusing food in social situations (2 respondents from two Dutch groups)</td>
</tr>
<tr>
<td></td>
<td>4. Better able to handle hindering social influences on other self-management domains such as smoking and taking walks (4 respondents from 4 Dutch groups)</td>
<td>Not observed</td>
</tr>
<tr>
<td>General objective</td>
<td>Patterns found in intervention group after participating in the intervention (n = 17)</td>
<td>Patterns found in control group after participating in the intervention (n = 10)</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td><strong>3. Increasing the engagement and support of the participants’ significant others in self-management.</strong></td>
<td>1. Significant others prepare healthy food for respondents more often (5 respondents from 3 Dutch and 1 Moroccan men group)</td>
<td>Wife now cooks healthier meals (1 respondent from a Dutch group)</td>
</tr>
<tr>
<td></td>
<td>2. Significant others help more with making healthy choices when buying groceries, and do not buy things they cannot have (4 respondents from 2 Dutch groups)</td>
<td>Significant others help more with making healthy choices when buying groceries (1 respondent from a Dutch group)</td>
</tr>
<tr>
<td></td>
<td>3. Relatives keep a closer watch on their food intake (7 respondents from 5 Dutch and 1 Turkish women group)</td>
<td>Not observed</td>
</tr>
<tr>
<td></td>
<td>4. More encouragement by relatives to eat (breakfast) on time, to exercise, and to use their medications (4 respondents from 2 Dutch, 1 Turkish women and 1 Moroccan men group)*</td>
<td>Not observed</td>
</tr>
<tr>
<td></td>
<td>5. Significant others engage in DSM activities such as eating breakfast together, taking medications together, and exercising (5 respondents from 2 Dutch, 1 Surinamese, 1 Turkish women and 1 Moroccan men group)</td>
<td>Not observed</td>
</tr>
</tbody>
</table>

* These results were confirmed in the interviews with the group leaders.
### TABLE 4 | The intervention strategies responsible for the experienced changes according to the respondents

<table>
<thead>
<tr>
<th>General objective</th>
<th>Intervention strategies during the intervention</th>
<th>How many and which participants considered these strategies responsible for the changes they experienced? (n = 17)</th>
</tr>
</thead>
</table>
| 1. Extending participants’ diabetes-related social networks, facilitating the exchange of social support and positive social influences. | **Group meetings for patients with diabetes, Phases 1 and 2**  
- Participants took part in interactive games and energizers (including walking together)  
- Participants were regularly invited to talk about their self-management problems and to ask group members for advice.  
- Participants were encouraged to phone and/or meet up with each other outside of the group meetings. | 9 respondents from 3 Dutch, 1 Surinamese and 1 Turkish women group  
8 respondents from 4 Dutch groups  
1 respondent from a Surinamese group |
| 2. Increasing participants’ abilities to handle social influences that hinder their self-management, such as norms, peer pressure, and temptations. | **Group meetings for patients with diabetes, Phase 1**  
- Group discussions (tips and tricks) were held about social situations in which managing diabetes is difficult  
- Participant practised these strategies with group members during role-playing exercises.  
**Group meetings for patients with diabetes, Phase 2**  
- An action plan was drawn up in which social influences and dealing with social influences played an important part (group meetings). Together with other group members, the person with diabetes came up with strategies and solutions to overcome these difficulties. | 5 respondents from 3 Dutch groups  
4 respondents from 2 Dutch, 1 Surinamese and 1 Turkish women group  
6 respondents from 3 Dutch and 1 Turkish women group |
| 3. Increasing the engagement and support of the participants’ significant others in self-management. | **Social network therapy session, Phase 2**  
- Together with their significant others, participants agreed on an action plan in which the significant others play an active role in their self-management.  
**Group meetings for significant others, Phases 1 and 2** | 5 respondents from 3 Dutch and 1 Turkish women group  
10 respondents from 5 Dutch, 1 Turkish women and 1 Moroccan men group |
After the intervention, only the intervention group reported to have influenced each other to improve their self-management, which resulted in a change in their norms for these behaviours. For example, reading food product labels together or exercising with group members made them feel more comfortable about doing this on their own (change of norms). Also, some respondents ($n = 3$) reported that they actively encouraged or were encouraged by group members to improve their self-management (e.g. positive peer pressure to take medications).

‘And we had one man, he was so resistant…. Even so, we were finally able to get him to take his medicine… he had pills, but he didn’t take them and his blood glucose just kept going up…. Then we told him, you have to do this, you have to do that, and he really listened to us.’ (Dutch woman, Dutch intervention group).

Furthermore, the majority of the respondents from the intervention group reported a continuous frequent exchange of emotional support. They reported that they still visit each other or plan to visit each other, exercise together, or get together as a group under the (voluntary) supervision of their group leader. When they see each other, they ask about each other’s well-being and experiences with diabetes.

I: And do you think you will stay in touch with group members?
R: Yes, I think so, yes. There is one woman in the E. (name of a building), I visited her once already. She is a very nice woman, I can really laugh with her (Surinamese women, Dutch intervention group).

I don’t have a spot on the camping site myself, but I visit friends of mine there. T. (group member) has a spot there too and I can drop by. That’s nice. We made an appointment about that. I think that’s nice (Dutch woman, Dutch intervention group).

Furthermore, both groups indicated that they phone each other, and when they run into each other on the street they ask each other how things are going.

There is one man, I still see him in the streets because he also lives here. And there is a woman, with whom I call sometimes. To ask how things have been, how thing are now. Yes I had a very nice group (Surinamese woman, Dutch intervention group).
‘When we see each other, we say, “Are you still doing everything, are you taking your pills?” “Give yourself your injections on time, take your pill on time.’ (Turkish woman, Turkish intervention group)

However, this seemed a more dominant theme among respondents in the intervention group. In addition, only they indicated that these contacts take place on a regular basis.

What was the mechanism behind these changes in social support? How did the intervention work? From the interviews with both the participants and the group leaders, it appeared that those in the intervention group were closer to each other and enjoyed the social interactions with group members more.

“You could really tell each other everything…. We really became such a tight group in that respect. You don’t feel embarrassed with each other, and everything was out in the open.’ (Dutch woman, Dutch intervention group).

Only the intervention group emphasized the pleasant atmosphere in the group and the high levels of trust between group members that facilitated the exchange of experiences and stories. More than half of the respondents mentioned that taking walks together and the ‘energizers (short breaks consisting of short exercises aimed to keep the participants motivated and concentrated during the rest of the program)’ that made them laugh contributed to this atmosphere. In contrast, the control group often reported feeling no special connection to group members, and used arguments that were more rational than emotional when talking about group members.

‘Well, you’re together with people who have the same thing. And there are people who’ve found solutions for certain things, and then I think, right, this is where you come into contact with people like this.’ (Dutch man, Dutch control group)

Finally, we observed an exchange of informational support in both groups: participants shared information and advice about diabetes, nutrition, medications, and blood glucose levels. Participants in both groups also liked to compare themselves with group members who were worse off. They were comforted by feeling they were not the only one with health problems and difficulties.

“So if you don’t feel so well yourself sometimes, then you think, well, don’t complain, because you’re not the only one who feels this way. That’s great, that’s really
Almost half of the respondents told that exchanging support, tips and tricks was stimulated during the meetings. They indicated that they were invited to discuss self-management problems and to advice others who were having difficulties with self-management behaviours.

2) Increasing participants’ abilities to handle social influences that hinder their self-management, such as norms, peer pressure, and temptations (General objective 2).

Before the intervention, most respondents in both groups were aware that they and their significant others shared the same unhealthy lifestyle. For most respondents, self-management meant behaving differently from their significant others. Peer pressure to eat too much or to eat unhealthy foods at social events was mentioned most often as this Moroccan woman (control group) describes:

“...Yes, but eat – you haven’t, you haven’t had anything to eat yet! Eat!” ... Then I say, sorry, I just ate. “Yes, but we invited you, so why did you eat at home?” ... You’re just trying to show them that you’re normal, too (Moroccan woman, Moroccan control group).’

The respondents also mentioned being confronted with food temptations, and to find it hard to eat on time at parties. Although some respondents dealt adequately with these social influences, most saw them as just the way things were or impossible to change.

After the intervention, the intervention group seemed better able to critically evaluate the impact of their social environments on their self-management. Both groups reported social influences from their significant others that hinder self-management, such as relatives who keep offering snacks or refuse to go on walks together, being lonely, and too many family responsibilities.

“He [husband] just eats and eats. And then he says, “What about you? Don’t you want anything?” I say no. “Don’t be ridiculous!” So I say, no, G. [name husband], I say, I promised I’d lose weight, remember? Well, I’m doing just fine. You heard him, didn’t you, when he asked me, “Do you want a biscuit?” No. “Do you want a biscuit?” No.’ (Dutch woman, Dutch intervention group)
However, in contrast with the intervention group most respondents in the control group did not seem to be aware that these influences hindered their self-management.

I: Do you (respondent and his family) also take each other's needs into account? 
R: Yes, but not really because there are more people in this household and they also need to be cooked for and I also come home at irregular hours sometimes.

Moreover, the intervention group also seemed to be aware of positive social influences on their self-management such as relatives who eat wholegrain rice without complaining. The intervention group also seemed better able to handle social influences that hinder their self-management. Both groups reported that they are now better able to resist temptations and pressure to eat unhealthy foods than before the intervention. However, only the intervention group named specific strategies they used in these situations, such as things they would say or arguments they would use.

‘In our family, it’s the custom to set everything down in front of you: “Take, take, take, have some of this, too, and some of that, too”… So I’ll say something like, “I took a class, and they told me I can’t have that. That’s why I’m not having any.’ (Turkish woman, Turkish intervention group)

These strategies were not observed in the control group.

‘Sometimes you’re with a group of people and you say, no, I won’t have anything, and then they start talking crap to you, things like, “Just have something for once, will you?” and then you have to stay strong, so to speak…. Yes, then I have to say no…. Yes, you have to go about things a little differently, it’s not easy, but it’s what you have to do. I: ‘So how do you do that, then?’ R: ‘Well, I just don’t do it.’ (Dutch man, Dutch control group)

The results thus indicate that due to the intervention, the participants in the intervention group were better able to handle social influences that would hinder them in their self-management. What elements in the intervention accounted for this effect?

A quarter of the respondents in the intervention group attributed these changes to the skills they learned in the role-playing exercises in which they practised being at
a party and refusing food being offered or things they would say if someone asked them why they did not eat.

‘No, I told them, I’m taking a class and that’s where I learned everything…. Sometimes they say, have a little, it’s so good. No, you don’t have to force me, I’ll have some if I want. And you shouldn’t force it on me (direct quote from roleplaying exercise). Yes, because we learned that, too…. Why do you offer me things? and so on.’ (Surinamese woman, Surinamese intervention group)

One third of the respondents mentioned the feedback and tips and tricks they received and shared with group leaders and members.

R: So I learned, make sure you’re not hungry (at a party) and drink a lot of water. If I am tempted I take a little sip of water.
I: Does that help?
R: It does help, because then I am distracted.
(Dutch woman, Dutch intervention group)

In addition, also the action plan that participants made with their relatives helped them to improve their self-management. This was also the case for behaviour other than food intake, for which only the intervention group reported being better able to handle social influences on these behaviours. Examples included smoking less even though their relatives discouraged them from doing this, and going out for a walk even if their spouse did not want to. When talking about these changes, one third of all respondents said they felt supported by the action plan they made with their relatives.

‘I try to [exercise more]. My wife is having a really hard time with it right now. She tries to, but um… Sometimes she doesn’t want to leave the house. Sometimes we just have to um... agree to do things (action plan) and then we do get out the door. Then we do it.’ (Dutch man, Dutch intervention group)

3) Increasing the engagement and support of the participants’ significant others in self-management. (General objective 3).

Before the intervention, most respondents of Dutch origin felt their diabetes was their own responsibility and seemed unaware that more support from significant others would make self-management easier. Only the Moroccan, Turkish, and Surinamese respondents believed more support would make self-management easier and regretted not receiving more support.
At the start of the intervention, both the participants and the group leaders indicated that, although the participants’ relatives understood the importance of taking medications, they knew little about physical activity, a healthy diet, or monitoring of blood glucose. Furthermore, most relatives seemed unaware of their own role in self-management, or felt that diabetes was the patient’s responsibility only. Some relatives wanted to offer support, but did not know how or felt that their help would not be accepted.

After the intervention, both the intervention and control group experienced more instrumental and appraisal support from their relatives. Their relatives prepare healthier food for them more often and help them make healthier choices when shopping for groceries. However, only the intervention group specified what their relatives changed about their cooking (less oil and salt, more vegetables).

‘Well, cooking, my wife used to use a lot of salt, but she doesn’t use much anymore…. And also fats, oil, she uses less oil now.’ (Moroccan man, Moroccan intervention group)

The intervention group also seemed to make deliberate choices about what and what not to buy when shopping.

‘Once in a while I’ll have some crisps, but we don’t buy crisps at all anymore. If we eat them, we eat them at someone else’s place. My wife even said so last week [when they were visiting someone], well, P., have some crisps here, because we don’t have them at home anymore.’ (Dutch man, Dutch intervention group)

‘And we also had a dietician [during the intervention], and she went to the store with us and told us what we had to watch for. That might sound strange, but since then I always read things when I’m in the supermarket [laughter]. And my husband does it too. To see if it’s actually, uh… you know.’ (Surinamese woman, Dutch intervention group)

The control group only added some healthy items to what they bought.

‘If we go grocery shopping now, we always get a head of lettuce, a cucumber, and a tomato. We never used to do that.’ (Dutch man, Dutch control group)

In addition, only the intervention group experienced more enabling social influences in their social environments since the intervention. Their relatives watch their
food intake more closely, and encourage them to eat breakfast (on time), exercise, and use medications correctly.

‘For example, you have a dessert, and then you have another one: “Mama, that’s bad for you. You eat a lot – eat a little less.”’ (Turkish woman, Turkish intervention group)

‘If I don’t feel like going to exercise class, “You really should, Mama, it’s good for your body’. (Surinamese woman, Surinamese intervention group)

Also, since the intervention the intervention group engages in self-management behaviours together with relatives (e.g. eating breakfast, exercising, or taking their medications together). This was not observed in the control group. This helps the respondents to maintain these activities.

R: ‘I started to exercise.’ I: ‘How did you do that?’ R: ‘Well, he (husband) and I joined a sport club […] Sometimes we walk together, but we also joined a.. what is it called? Fitness…. we do fitness now.’ I: ‘And how do you maintain exercising?’
R: ‘We do it together now, you know, my husband and me.’ (Surinamese women, Dutch intervention group)

These results indicate that the intervention promoted the integration of the social network of the participants in their diabetes self-management behavior. Which elements of the intervention accounted for this effect? The majority of the respondents attributed these changes to the family meetings and to the group leader, who talked with their relatives about making changes. They did not specify which elements of these meetings contributed to these changes. On third of the respondents mentioned the action plans they made together with their relatives.

‘My goal [in the action plan] was to have breakfast in the morning. That’s something I never did…. R [husband] and my grandmother [who lives in the same house], she also has to eat in the morning, and then we started eating in the morning’ (Dutch woman, Dutch intervention group)
DISCUSSION

The intervention group was influenced by other group members to change their norms towards self-management, and their self-management itself. Also, the exchange of emotional support continued after the intervention has ended. Intervention strategies that contributed to these changes were practising self-management with and encouragement from group members, walking together and energizers that created a pleasant atmosphere and high levels of trust in the groups. The intervention group seemed better able to recognize and prepared for social influences on self-management and better able to deal with more diverse social influences on self-management. The skills learned through role-playing exercises, as well as receiving feedback from group members and making an action plan with relatives contributed to these changes. Finally, only the intervention group reported that relatives watch them more closely, encourage them to perform self-management behaviours and engage in these behaviours with them. Making an action plan together, having relatives participate in family meetings, and listening to group leaders contributed to these changes.

Strengths and limitations

In this under-explored area, this study provides an exploration of the intervention strategies underlying the effects of a group-based intervention. However, given the qualitative design, this study does not allow a firm conclusion about the causality of the observed changes in relation to the intervention. The positive results do, however, justify the value of developing a randomized controlled trial to quantitatively test the effect of the intervention Powerful together with diabetes.

In addition, this study only reports on intervention strategies that actually contributed to the changes in social support and social influences regarding the participants’ self-management. This might suggest bias because of an assumption that the intervention was effective. During the interviews, the participants found it challenging to link changes in social support for and social influences on their self-management to specific intervention strategies. Although they were able to mention practical aspects of the intervention that did not work (such as that they did not identify with the multi-cultural character of an educational video), they did not identify intervention strategies that did not lead to a change in determinants. This is likely to be caused by the abstract nature of this type of questions. In hindsight, knowing that we have not been able to test the effectiveness quantitatively, this study could have been strengthened by studying intervention strategies that
did not contribute to changes in social support for and social influences on self-management through other qualitative research methods as well.

Also, the respondents of the qualitative study have a slightly higher income, education, and have better self-rated diabetes-related health compared to the general study population. However, these differences are small and the respondents of the qualitative study can still be considered socioeconomically deprived despite these differences. Therefore we have no reason to assume that the intervention strategies might have worked better or worse among this population than among the entire study population, thus biasing the results of this study.

Further, the respondents were interviewed right after the end of the intervention which gives no indication of long term intervention effects. Also, the participants’ accounts might be subjected to recall bias, because of the length of the intervention. However, in both groups, only one respondent reported difficulties with remembering the intervention in detail. Furthermore, the majority of the results found in the interviews with the participants were verified by the interviews with group leaders, and did not lead to other conclusions.

In our intervention, emotional support, promoted by a pleasant atmosphere in the group, appeared to be crucial for improving diabetes self-management. Interestingly, the participants received emotional support primarily from group members rather than from relatives or friends. Other studies have also shown that peer support is important for diabetic patients because it gives them the opportunity to share similar experiences and specific concerns\textsuperscript{22-24}. Relatives might not be able to provide emotional support because they do not have diabetes themselves or experience the disease differently. This is confirmed by other studies. Spouses and relatives of patients might have different concerns and ideas about self-management than the patients\textsuperscript{25}. Carter-Edwards shows that among African American women with type 2 diabetes relatives care, but often do not understand, which is why these women do not get the support they need\textsuperscript{26}.

Practising difficult situations together through role playing and then giving each other feedback appeared to be a promising element of the intervention. This might have made the participants more confident that they could implement these strategies in their own social environments. This is in accordance with other studies that show that preparing coping plans is necessary for making and maintaining lifestyle changes\textsuperscript{27}. In addition, focusing on behaviour-related tasks and feedback
is one of the features that seem successful in interventions that try to improve self-management among socioeconomically deprived patients²⁸.

Many tasks related to self-management take place in interaction with relatives, and the involvement of spouses in particular can be an important source of practical support. However, relatives can also function as a source of stress and interference when they undermine rather than facilitate self-management²⁹. Therefore, although actively involving relatives is likely to improve self-management behaviours, to our knowledge there are no studies that discuss the best ways to involve relatives of patients in socioeconomically deprived neighbourhoods in these behaviours. In this intervention, making an action plan together and implementing and optimizing it over time seemed to increase communication about self-management, and with this came awareness of the relatives’ specific role in self-management. The action plan was very specific and made it easier to reach actual agreements about self-management together, which increased the involvement of relatives (e.g. more attention to self-management, encouraging and engaging in self-management behaviours).

CONCLUSIONS

This group-based intervention ‘Powerful together with diabetes’ seems to increase social support and diminish hindering social influences on self-management in socioeconomically deprived patients with type 2 diabetes. Promising elements of the intervention were skills training and providing feedback using role-playing exercises in group sessions with patients, as well as the involvement of patients’ significant others in self-management tasks, and actively involving them in making an action plan for self-management. These positive results justify the value of further evaluating the effectiveness of the intervention in a larger sample.

CONTRIBUTORSHIP STATEMENT

CV coordinated the study, and developed the intervention, constructed the design, and drafted the manuscript. KS developed the study, constructed the design, and revised the manuscript. GN, PJMU, BJCM participated in the design of the study and revised the manuscript. M.J.E.K. coordinated part of the study and participated in the analyses of the study. M.A.H. participated in the analyses of the study. VN de-
developed the study, constructed the design, and revised the manuscript. All authors read and approved the final manuscript.

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COMPETING INTERESTS

We have read and understood BMJ policy on declaration of interests and declare that we have no competing interests.

FUNDING

This work was supported by the Netherlands Organisation for Health Research and Development (ZonMw) (project number ZonMw 76500003).

DATA SHARING STATEMENT

Patient level data (qualitative in depth interviews) are available from the corresponding author. Informed consent for data sharing was not obtained but the presented data are anonymized and risk of identification is very low.
REFERENCES


ADDENDUM 1

TOPIC LIST: PARTICIPANTS

1. How did you experience the intervention?
   a. Recruitment process?
   b. Group meetings?
   c. Meetings for significant others?
   d. Network meetings?
2. What did you like most? Why?
3. What did you like less? Why?
4. Would you recommend the intervention to other people?
5. Social network meetings?
   a. What was discussed?
   b. Experiences?
6. Meetings for significant others?
   a. How were significant others introduced?
   b. What was their reaction?
7. Group leader?

EXPERIENCED EFFECTS

1. What have you learned?
2. What effect do you think the intervention has had on you?
   a. On your diabetes? What? How did this happen?
   b. On your body? What? How did this happen?
   c. Diabetes self-management? What? How did this happen?
   d. Other things? What? How did this happen?
   e. Where do you think that comes from? What has contributed the most to this?
DEALING WITH DIFFICULT SITUATIONS

1. How did you deal with difficult situations before the intervention?
2. How do you deal with difficult situations now?
3. What do you think about these changes?
4. How do you think these changes occurred? How exactly did you learn that?
5. What could be improved about the way you deal with difficult situations?
6. What do you need for this?

CONTACT WITH GROUP MEMBERS

1. What sort of contact did you have with your group members?
   a. How did you experience this?
   b. What did you like/not like?
   c. Do you still see some of the people in your group?
2. Did you make friends during the intervention?
   a. With whom?
   b. How did that happen?
   c. What does this friendship involve?
   d. What activities do you do together for diabetes self-management (support, movement, eating)?
   e. Do you think you will continue to see each other in the future?
3. You did not make friends: why not? A need for friends? What do you need to make new friends?

FAMILY AND FRIENDS

1. Did your significant other participate in the intervention? What did they think about it?
2. How can you tell that they participated in the intervention?
3. How did they deal with your diabetes before they participated in the intervention?
4. How do they deal with your diabetes now?
5. How do they do that now? Has anything changed? How did this happen? What role did the intervention play?
ADDENDUM 2

TOPIC LIST: GROUP LEADERS

1. In general, how did you experience the intervention?
2. How did your participants do during the intervention (discussion of each participant)?
   a. Experiences
   b. Goals they worked on
   c. Changes in participants during the intervention
   d. Social interactions between participants
   e. Which participants did/did not benefit from the intervention and why
3. What was your role in creating the group feeling (adequately promoted? how?)
4. Did you feel that you had sufficient knowledge (e.g. own experience, training, and support from AMC) to carry out the intervention?
5. Experience with the manual (understandable? adequate/not adequate? what could be improved?)
6. Experience with the organization by AMC (availability of material, location, facilities)
7. Facilitators and barriers during implementation? How did you handle these? Do you think sufficient action was taken?
8. What were successful/ unsuccessful elements of the interventions? Why?
The impact of a social network based intervention on self-management behaviours among patients with type 2 diabetes living in socioeconomically deprived neighbourhoods. A mixed methods approach.

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Based on:

The impact of a social network based intervention on self-management behaviours among patients with type 2 diabetes living in socioeconomically deprived neighbourhoods. A mixed methods approach.

Accepted for publication in Scandinavian Journal of Public Health
ABSTRACT

Aims

This study aimed to explore the effect of the social network based intervention Powerful Together with Diabetes on diabetes self-management among socioeconomically deprived patients. This 10-month group based intervention targeted both patients and their significant others and aimed to improve self-management by stimulating social support and diminishing social influences (peer pressure, social norms) hindering self-management.

Methods

This intervention was evaluated in a quasi-experimental study using a mixed methods approach. Of 131 socioeconomically deprived patients with suboptimal glycaemic control, 69 were assigned to the intervention group and 62 to the control group (standard diabetes education). 27 qualitative in depth interviews with participants and 24 with their group leaders were held to study the subjective impact of the intervention. Further, self-management behaviours were assessed at baseline, 10 and 16 months. Qualitative data was analysed using Maxqda. Quantitative data was analysed using SPSS and R2.

Results

Qualitative data showed that the intervention group had better understanding of the way self-management influences diabetes. The intervention group showed more complex self-management behaviours such as planning ahead, seeking adequate food and physical activity alternatives, and consistently taking their diabetes into consideration when making choices. In participants with complete follow-up data, we found a significant increase in physical activity in the intervention group and no changes in medication adherence and diet.

Conclusions

This study indicates that an intensive support group and simultaneously involving significant others might improve diabetes self-management behaviours among socioeconomically deprived patients. Further studies are needed to justify further implementation of the intervention.
The impact of a social network based intervention on self-management behaviours among patients with type 2 diabetes living in socioeconomically deprived neighbourhoods. A mixed methods approach.

BACKGROUND

People in lower socioeconomic groups are disproportionately affected by type 2 diabetes and its complications. A poorer glycaemic control related to less adequate self-management behaviours partly accounts for these increased risks. Coping with type 2 diabetes requires extensive self-management skills: adherence to dietary advice and medications, engaging in regular physical activity, quitting smoking, and prevention or treatment of hypoglycaemia. However, compliance with and maintaining such complex health regimens is especially challenging for socioeconomically deprived patients due to lower health literacy, low knowledge of blood glucose targets, and lower self-efficacy.

Interventions that focus on self-management behaviours seem to contribute to short term glycaemic control, also among socioeconomically deprived patients, but long term, sustainable effects are scarce. Socioeconomically deprived patients seem to experience difficulties with maintaining newly learned behaviour after participating in an intervention.

Interventions that target social influences on self-management behaviours might be promising in terms of sustainability of the desired behaviour change. Social interactions with friends and family members have a major impact on self-management. Social support can positively influence self-management, but significant others can also hinder self-management by nagging about or paying too much attention to self-management. Socioeconomically deprived patients seem to have fewer sources of social support in their social environments and often receive insufficient social support, which is needed to improve adherence. In addition, they are often confronted with social influences from their immediate social environments that hinder self-management (e.g. peer pressure, specific cultural beliefs and expectations, and fewer positive role models).

These patients might benefit from an intervention focusing on social support and social influences on self-management. To our knowledge there are no interventions that focus on social support and hindering social influences at the same time. Therefore, Powerful Together with Diabetes was developed which focused on increasing...
social support for self-management and decreasing social influences hindering self-management to improve self-management behaviours.

Further, our needs assessment showed that patients from socioeconomically deprived groups have specific educational needs that need to be targeted [unpublished] such as low motivation for and low outcome expectations regarding education, difficulties with remembering new information, a low priority for diabetes self-management, a desire for practical information, reading and writing difficulties, and differences in knowledge about diabetes. This is confirmed by an increasing amount of studies that recognise that these groups might need interventions that go much further than traditional diabetes education regarding time, costs, effort, and interactions with professionals.

Based on this needs assessment, the intervention was specifically targeted to patients from socioeconomically deprived neighbourhoods, and culturally targeted to the Dutch, Turkish, Moroccan, and Surinamese patients in this group. It lasted 10 months and was delivered group based.

In the evaluation of this intervention we use a mixed methods approach. We adjusted our research methods to our target population. Previous studies show that socioeconomically deprived patients often have difficulties understanding and filling out questionnaires. Other questionnaire formats (e.g. open questions) might be more suitable.

Further, existing questionnaires often focus on self-management to explain potential differences in metabolic control. This might be useful to explain changes in Hba1c but might also limit the possibility to study other changes in self-management which might provide important starting points to understand the effects of an intervention. Therefore we chose for a broader evaluation of this intervention by using both qualitative and quantitative methods.

This paper reports on the effects of this intervention on medication adherence, diet, and physical activity. To study these changes we use both qualitative and quantitative data.
METHODS

The Powerful Together with Diabetes intervention was evaluated in a quasi-experimental study with a control group that received a standard group based educational intervention. The design is described elsewhere. Because the intervention required the participants to live close to each other and the recruitment of participants proved to be difficult, (cluster) randomization was impossible. The intervention and control groups were matched on gender, ethnicity, and organization of diabetes care in the GP practice. The main outcome measures were HbA1c, collected from participants’ medical files, and quality of life. Contrary to our expectations, HbA1c and other biomedical markers were not measured as regularly by general practitioners as prescribed by the national GP standard for diabetes care. Therefore, the effect on HbA1c could not be studied.

The intervention group followed Powerful Together with Diabetes and the control group followed Know Your Sugar. This study was approved by the Medical Ethics Committee of the Academic Medical Center (AMC) in Amsterdam and is registered in the Dutch Trial Register NTR1886.

Patients were selected from the records of 39 general practices in socioeconomically deprived neighbourhoods in four Dutch cities when they met the following criteria: aged ≥ 35 years, type 2 diabetes for ≥ 1 year, suboptimal glycaemic control (HbA1C > 53 mmol/mol). Excluded were patients with severe psychiatric disorders, unable to come to the intervention location, or planning to stay abroad for ≥ 6 weeks during the intervention period. All potential participants that fit the eligibility criteria were invited to an information meeting by a letter from their GP. After this meeting they decided on participation and provided written or oral consent (Fig. 1).

The intervention and control group
Both interventions were conducted in groups with 7-10 participants, guided by a trained group leader and culturally targeted to Dutch, Surinamese, Turkish and Moroccan patients.

Powerful Together with Diabetes: Intervention group
The intervention was developed according to Intervention mapping. It lasted 10 months and consisted of 24 group meetings for participants, 6 group meetings for their significant others and two social network therapy sessions in which both the participant and a significant other were present. The intervention was group based, with 7-10 participants per group. Each group was guided by a group leader.
The intervention aimed to improve diabetes self-management by increasing knowledge, positive outcome expectations, self-efficacy, and skills associated with diabetes self-management. Since the social environment of patients influences these determinants and plays an important role during self-management important intervention objectives were to get the participants to support and positively influence each other to better manage their diabetes, to handle social influences hindering self-management and to engage relatives and friends more in self-management.

Further, the intervention strategies were tailored to socioeconomically deprived patients. A key aspect of the intervention was the underlying group process. The participants were addressed as a (learning) group, and learned and practised all new behaviours and coping strategies together to stimulate social support, be more receptive to learning, and to make learning more fun. The group leaders used an inductive educational approach (the participants practiced with a problem while the group leader added information and theory to their understanding if necessary) to increase curiosity and tailor the information to the participants’ needs. Particular attention was paid to recognizing and dealing with influences on self-management in the immediate social environment (peer pressure, social norms).

Further, non-traditional intervention strategies were used, such as games, quizzes, role playing, skills training with guided practice and (fun or relaxing) energizers to optimize the attention span. To ensure a close connection to their interests, the group leaders actively involved participants in the intervention through active learning. A limited amount of information was provided at each meeting and information from previous meetings was repeated (box 1 and 2).

Powerful Together with Diabetes was realized in 10 groups from August 2010 through December 2011. All groups finished the intervention, except for the Moroccan male group which ended due to lack of motivation among the participants.
Figure 1 Overview of the flow of the study with regard to self-management measures
**Chapter 5**

**Box 1. Program components: phase 1**

**Review of the last meeting and exchange of experiences: 10-15 min**
At the start of each meeting, the group leader discusses how the period since the last meeting has been experienced and how the participants worked on their homework. The participants were stimulated to ask questions, exchange experiences and help each other with their homework.

**Collection of questions: 5-10 min**
To guarantee that the meeting fits the needs of the participants, the group leaders start with a short description of the meeting and write down the participants’ questions on this topic. At the end of the meeting, the group leader checks whether all questions have been addressed.

**Sharing positive news: 5 min**
To make participants more open for new information, they share their positive news of the week with each other (self-affirmation). This news could be anything, as long as it was experienced as being positive by the participant.

**Diabetes game: 15-35 min**
Many meetings contained a knowledge game. The participants participate in a quiz or a game, often teaming up and competing with each other. The group leader provides only that information that participants asked for themselves. The aim is to provide participants only with information that they need, and prevent giving an overload of information. The information provided was supported by large-sized posters/visual aids on diabetes-related topics.

**Nutrition game: 60 min**
The participants were divided in groups and given plastic cards with photographs of dishes and food-stuffs, divided into breakfast, dinner, lunch, snacks, beverages, and others. Each card could be placed on one of three piles: green (eat as often as you like), orange (eat to a limited extent), and red (try to avoid, eat very rarely). The assignment was to place these cards on the appropriate pile; this was followed by discussing with each other the placing of the cards.

**Letter of the week: 20-45 min**
The ‘letter of the week’ is a fictional letter received from someone with diabetes who has a problem that needs to be solved. The participants were invited to brainstorm together about the problem and help solve the problem. The letter of the week was used to uncover tacit views of participants and provide them with solutions that they could also apply themselves.

**Role playing: 20 min (on average)**
Every meeting contained a role-playing exercise in which the participants practised a difficult situation together. The participants could also provide role-playing scenarios themselves (e.g. difficult situations they were personally confronted with). Each exercise ended with the exchange of advice and tips & tricks the participants could use in their own situations.

**Energizers: 5-15 min**
Energizers included passing a ball along and giving the person who receives the ball a compliment, balancing on a balloon to feel all muscles in the body, playing ‘web of life’ (a game illustrating that we need each other), keeping a balloon up in the air, etc. The aim of these energizers is to stimulate bonding between group members and refresh the participants to enable them to absorb new information again.
A mixed methods approach

Exercising with participants: 30 min
To show the participants how to exercise for 30 min and let them experience this, group leaders walk with the participants for 30 min each meeting in the neighborhood (i.e. the participant’s own neighbourhood). The group leaders were instructed to walk among the participants, so that they could talk to everyone.

Weighing pros and cons: 15-20 min
To change outcome expectations, participants brainstorm with each other about the pros and cons of certain behaviours (e.g. refusing food at a party). This is achieved through group discussions, sometimes using a whiteboard to count the pros and cons. The group leader aims to emphasize the pros to stimulate positive outcome expectations.

Homework
The participants received homework at the end of each meeting. They were encouraged to pay attention to certain things (e.g. are there times when you smoke more than usual), or to try to meet up with individual participants outside the group meetings.

Cookbook
The recipes of all participants were collected and compiled as a cookbook and given to participants during the intervention. The cookbook also contained information about choosing healthy ready-to-eat meals for participants that did not cook.

Summarizing results and complimenting participants: 10 min
To help participants feel they have spent their time well, helped each other and have learned a lot, at the end of each meeting the group leader summarizes what the participants have learned. Group leaders also tell the participants how proud/appreciative they are of all their achievements.

BOX 2. | Program components: phase 2

Homework
In phase 2 the participants’ homework consists of keeping diaries, working on behavioral goals, and staying in contact with each other in the weeks without an intervention meeting.

Keeping a diary
For this intervention, special diaries were developed. They consisted of an outline of each day, which participants were asked to fill in: for this purpose, participants could use stickers, drawings or, if possible, writing. For example, for smoking there were stickers showing cigarettes, for physical activity stickers with a ‘10’ (for 10 min), and stickers with different colors for various medications. The nutrition diaries could be filled in by writing or with a drawing.

Group exercise: 30-45 min
The group exercises consisted of assignments the participants were asked to do in small groups (± 3 participants). The aim was to let the participant practice and ask each other for feedback in a non-threatening environment, before sharing their experiences in the group. The exercises also aimed to make clear what the participants were struggling with, and provide group leaders with guidelines for further explanations.
Know your Sugar: Control group

Know your Sugar lasted six weeks and consisted of six group meetings for the participants, and was based on standard diabetes education in the Netherlands. In the Netherlands, standard education for patients with type 2 diabetes consists of information and education about type 2 diabetes and self-management from the GP, GP assistant or diabetic nurse. Further, patients are advised to quit smoking, to regularly exercise, to lose weight when having a BMI > 25 kg/m², and to eat healthy for which they are referred to a dietician. It aimed to provide the participants with the information they needed to manage their diabetes. Though it provided the participants with the opportunity to get to know other patients, to influence each other and to exchange social support, it did not specifically target these determinants or intervene in the immediate social environments of participants. Know your Sugar was realized in 9 groups from January 2011 through November 2011. All groups finished the intervention; however, the Moroccan male group did not start due to a lack of interest among the potential participants.

Action plan

The action plan comprised 6 parts: it contained many pictures and consisted of outlines the participants had to fill in. Participants who could not write were teamed up with someone that could. The participants were not given all parts of the action plan at once, to prevent them from getting discouraged. They were given a portfolio in which they added a part of their action plan each meeting; in this way they were not confronted with all the work they still had to do, but could see their work growing.

Part 1: Choosing a behavioral goal, making it specific, determining who could help with this goal, and thinking of a reward when achieving this goal.

Part 2: Determining two important barriers to achieve the behavioral goal (some of the barriers were already mentioned in the action plan for the participants to mark). For each barrier the participant has to create five solutions (with group members).

Part 3: Determining important barriers in the immediate social environment to achieve the behavioral goal and thinking of solutions.

Part 4: Thinking about ways significant others can help with diet, physical activity, taking medications, monitoring of blood glucose, and quitting smoking or smoking less.

Part 5: Updating the action plan according to keeping a diary and comparing this diary with the one filled out at the start of phase 2.

Part 6: Determining risky situations in the near future (the coming 2 weeks) and making plans to overcome these risky situations.

Part 7: Determining two new risky situations in the near future (the coming 2 weeks) and making plans to overcome these risky situations.
Both interventions were guided by different group leaders who were matched with the participants based on ethnicity and gender. The group leaders were recruited through an advertisement and selected based on their prior experience with group based education. The group leaders of the Dutch groups were diabetes nurses, GP assistants and physician assistants. The group leaders of the Moroccan, Turkish and Surinamese groups were lay health educators. Prior to the intervention, the group leaders of the intervention group received an eight-hour training and the group leaders of the control group a two-hour training. Both trainings focused on the implementation of the intervention. They differed in length due to the length (10 months) and complexity of Powerful Together with Diabetes.

**Study design of this paper**

This paper reports on the data of the secondary outcome measures: medication adherence, diet and physical activity. We used both qualitative and quantitative data to explore the effects of the intervention on these self-management behaviours, using a mixed methods approach. First we explored what effects on self-management were reported by participants. Then, we checked if we could confirm these findings quantitatively.

**Part 1: Qualitative study**

**Recruitment of participants**

In-depth semi-structured qualitative interviews were held with participants from the intervention and control group, and with the group leaders between January 2011 and January 2012. Because this is a hard to reach study population, the group leaders were asked to select and invite the respondents. We asked them to invite two participants that had been attending the intervention regularly and who had significant others that also participated in the intervention.

In total, 27 participants agreed to be interviewed: 17 participants from 8 intervention groups (11 Dutch, 2 Turkish women, 2 Moroccan men, and 2 Surinamese) and 10 participants from 6 control groups (7 Dutch, 2 Moroccan women, and 1 Surinamese). 11 participants refused to participate. They lacked the time to participate, were on holiday or felt like they had spent enough time on the study procedures (filling out questionnaires and the physical exam). These respondents broadly reflected the wider trial population in terms of age, gender, duration of diabetes, and glycaemic control (see Table 1). Each interview lasted on average 40-60 min.
Response among group leaders \((n = 15)\) was 100%. The group leaders of the control group \((n=6)\) were interviewed once. The group leaders of the intervention group \((n=9)\) were interviewed twice to prevent memory bias that might be caused by the length of the intervention, during the intervention and after the intervention. The interviews lasted on average 60-90 minutes each.

**Data collection**

All interviews took place at the respondents’ homes or, if preferred by the respondents, at the intervention location (a community centre). The interviews were conducted by C.V. and M.J.E.K. with the help of an interpreter (Turkish interviews) or a Moroccan interviewer who had received training prior to the data collection. The Moroccan interviewer met the respondents before during other study procedures. The respondents met C.V. and M.J.E.K. during the observations in the intervention. Also, C.V. and M.J.E.K. had regular contact with the group leaders during the implementation of the intervention. The interviewers introduced themselves with little background information and emphasized they had no competing interest while conducting the interviews. They focused their introduction on wanting to evaluate the intervention and wanting to hear all (both positive and negative) experiences with the intervention.

All interviews were supported by a topic guide and audiotaped, with the respondents’ consent. Relevant topics for the participants included experiences with the intervention, and changes in self-management behaviours. Relevant topics for the group leaders included experiences with the intervention, and changes in self-management behaviours among the participants in their groups (see addendum 1 and 2).

**Analysis**

Analysis of the interviews with the participants was done by three researchers using MAXQDA 21. The first coding was done by C.V. and checked by M.J.E.K; consensus was reached by discussion. Another researcher (M.A.H.) who was blinded for the intervention or control group, randomly checked their coding to preclude bias.

We constructed an initial conceptual framework based on the self-management behaviours targeted by the intervention (medication adherence, physical activity and diet). The data were coded according to this framework 22. To determine whether the intervention’s general objectives had been achieved, the interviews were searched for patterns regarding the sub-goals. When a pattern was found in one group, the researchers tried to find the same pattern in the other group as well. When patterns were found only in the intervention group, they were considered to be an indication
that these patterns, or differences in patterns, had been caused by the intervention 
*Powerful Together with Diabetes*.

The interviews with the group leaders were used to check and consolidate the find-
ings that emerged from the interviews with participants through data triangula-
tion. After determining relevant patterns in the interviews with participants, we 
checked if these findings could be confirmed by the interviews with group leaders.

**TABLE 1 | background characteristics of the participants in this study**

<table>
<thead>
<tr>
<th></th>
<th>Quantitative study (n=131)</th>
<th>Qualitative study (n=27)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intervention group (n=69)</td>
<td>Control group (n=62)</td>
</tr>
<tr>
<td><strong>Age in years (SD)</strong></td>
<td>61.15 (10.4)</td>
<td>62.3 (9.9)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>66.1%</td>
<td>69.8%</td>
</tr>
<tr>
<td><strong>Total household income per month</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>€454–€1,270</td>
<td>34.8%</td>
<td>46.8%</td>
</tr>
<tr>
<td>€1,270–€1,906</td>
<td>30.4%</td>
<td>25.8%</td>
</tr>
<tr>
<td>More than €1,906</td>
<td>10%</td>
<td>9.7%</td>
</tr>
<tr>
<td>Would rather not say</td>
<td>24.6%</td>
<td>17.7%</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnic Dutch</td>
<td>40.6%</td>
<td>27.4%</td>
</tr>
<tr>
<td>Surinamese</td>
<td>11.6%</td>
<td>32.3%</td>
</tr>
<tr>
<td>Turkish</td>
<td>10.1%</td>
<td>16.1%</td>
</tr>
<tr>
<td>Moroccan</td>
<td>15.9%</td>
<td>6.5%</td>
</tr>
<tr>
<td>Other</td>
<td>8.7%</td>
<td>9.7%</td>
</tr>
<tr>
<td>Missing</td>
<td>13%</td>
<td>8.1%</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No formal education/primary education</td>
<td>50%</td>
<td>52.6%</td>
</tr>
<tr>
<td>Lower secondary vocational education/ preparatory secondary vocational ed.</td>
<td>20.3%</td>
<td>21.1%</td>
</tr>
<tr>
<td><strong>How would you describe the state of your diabetes?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very good</td>
<td>5%</td>
<td>4.4%</td>
</tr>
<tr>
<td>Good</td>
<td>36.7%</td>
<td>40.4%</td>
</tr>
<tr>
<td>Reasonable</td>
<td>40.0%</td>
<td>44.4%</td>
</tr>
<tr>
<td>Poor</td>
<td>13.3%</td>
<td>11.1%</td>
</tr>
<tr>
<td>Very poor</td>
<td>5%</td>
<td>0%</td>
</tr>
<tr>
<td><strong>HbA1c at baseline mmol/mol (SD)</strong></td>
<td>62 /7.80 % (1.1)</td>
<td>63 /7.95 % (1.7)</td>
</tr>
<tr>
<td><strong>Duration of diabetes in years (SD)</strong></td>
<td>8.36 (8.0)</td>
<td>11.65 (10.2)</td>
</tr>
</tbody>
</table>

**Part 2 Quantitative study**

**Data collection**

A structured questionnaire was administered at baseline, 10 and 16 months. The 
questionnaire consisted of existing questionnaires that were validated among this
Chapter 5

A target population or a population related to the target population. The questionnaire was administered in the mother tongue of the participants (Turkish, Berber, Moroccan Arabic).

Diabetes self-management was measured using the Summary of Diabetes Self-Care Activities Measure (SDSCA) which covers the following behaviours: 1) medication adherence (two questions), 2) diabetes-specific diet (three questions), 3) general diet (two questions), and 4) physical activity (two questions) \(^{24}\). Respondents could assess their adherence to self-management skills for each item on a scale ranging from 0–7 days in the previous week and, for one question on diet, also the average days per week in the previous month (box 3). We excluded questions on insulin injections, foot care and smoking because not everyone in the intervention used insulin and foot care and smoking were not the main focus of the intervention.

**BOX 3 | Questions on diabetes self-management**

<table>
<thead>
<tr>
<th>Diet</th>
<th>How many of the last SEVEN DAYS have you followed a healthful eating plan?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td></td>
<td>On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?</td>
</tr>
<tr>
<td></td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td></td>
<td>On how many of the last SEVEN DAYS did you space carbohydrates evenly through the day?</td>
</tr>
<tr>
<td></td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td></td>
<td>On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables?</td>
</tr>
<tr>
<td></td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td></td>
<td>On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products?</td>
</tr>
<tr>
<td></td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exercise</th>
<th>On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td></td>
<td>On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?</td>
</tr>
<tr>
<td></td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Medications</th>
<th>On how many of the last SEVEN DAYS did you take your recommended insulin injections?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
<tr>
<td></td>
<td>On how many of the last SEVEN DAYS did you take your recommended number of diabetes pills?</td>
</tr>
<tr>
<td></td>
<td>0 1 2 3 4 5 6 7</td>
</tr>
</tbody>
</table>
Educational level was indicated by the highest educational level attained, using nine categories ranging from no formal education/primary education to scientific/university education. Total household income consisted of the summed income of every member of the household after deduction of taxes. Ethnicity was established by asking the respondents for their own country of birth, and that of their father and mother. Respondents who were born in the Netherlands and whose both parents were born in the Netherlands, were assumed to be of Dutch origin. A subjective assessment of the diabetes status was measured using five categories ranging from ‘very good to ‘very poor’. Duration of diabetes (in years) was self-reported. Data on HbA1C levels of the participants were obtained from the medical files 17.

Internal consistency was calculated for all subscales of the SDSCA. Based on these analyses, we excluded the third question related to the diabetes-specific diet and decided not to combine the items for general diet. The two questions on medication adherence were combined into one variable, because of a negative covariance.

**Analyses**

In the current analyses, we included those who participated in the baseline measurement, and the follow-up measurements at 10 and 16 months (figure 1). To evaluate potential selection bias, baseline characteristics of the participants included in the analyses were compared with those excluded from the analyses (Table 2).

A linear mixture model was used to describe the changes in means within and between the intervention group and control group. We adjusted for baseline scores on medication adherence, physical activity, diabetes-specific diet, and fruit, vegetable and consumption of full-fat products. The group to which the participant belonged during the intervention was chosen as a level in the model.

All analyses were performed using SPSS 19.0 (SPSS Inc., Chicago, Illinois, USA) and R2 13.1 (R Foundation for Statistical Computing). A p-value of <0.05 was considered to be statistically significant.
### TABLE 2. | Characteristics of study participants included and excluded from analyses per intervention arm

<table>
<thead>
<tr>
<th></th>
<th>Intervention group (n=69)</th>
<th>Control group (n=62)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Included in analysis (n=40)</td>
<td>Excluded from analysis (n=29)</td>
</tr>
<tr>
<td><strong>Age in years</strong></td>
<td>60.7 (10.0)</td>
<td>61.5 (10.6)</td>
</tr>
<tr>
<td><strong>Gender (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>67.5</td>
<td>62.1</td>
</tr>
<tr>
<td><strong>Income (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>€454-1270</td>
<td>27.5</td>
<td>34.5</td>
</tr>
<tr>
<td>€1270-1906</td>
<td>32.5</td>
<td>6.9</td>
</tr>
<tr>
<td>Higher than €1906</td>
<td>32.5</td>
<td>10.3</td>
</tr>
<tr>
<td>Unknown</td>
<td>7.5</td>
<td>48.3</td>
</tr>
<tr>
<td><strong>Education (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No education/primary education</td>
<td>41</td>
<td>59.1</td>
</tr>
<tr>
<td>Lower vocational education</td>
<td>23.1</td>
<td>18.2</td>
</tr>
<tr>
<td><strong>Ethnicity (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnic Dutch</td>
<td>40</td>
<td>41</td>
</tr>
<tr>
<td>Surinamese</td>
<td>20</td>
<td>0</td>
</tr>
<tr>
<td>Turkish</td>
<td>12.5</td>
<td>7</td>
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<tr>
<td>Moroccan</td>
<td>12.5</td>
<td>21</td>
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<tr>
<td>Other</td>
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<tr>
<td>Missing</td>
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<td>31</td>
</tr>
<tr>
<td><strong>How would you describe the state of your diabetes? (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very good</td>
<td>7.5</td>
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</tr>
<tr>
<td>Good</td>
<td>35</td>
<td>27.6</td>
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<tr>
<td>Reasonable</td>
<td>37.5</td>
<td>31</td>
</tr>
<tr>
<td>Poor</td>
<td>12.5</td>
<td>10.3</td>
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<tr>
<td>Very poor</td>
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<tr>
<td>Missing</td>
<td>0</td>
<td>31</td>
</tr>
<tr>
<td><strong>HbA1c % (SD)</strong></td>
<td>7.6 (0.9)</td>
<td>8.0 (1.3)</td>
</tr>
<tr>
<td><strong>HbA1c (Mmol/mol)</strong></td>
<td>59</td>
<td>63</td>
</tr>
<tr>
<td><strong>Duration of diabetes in years (SD)</strong></td>
<td>9.7 (8.8)</td>
<td>5.65 (5.4)</td>
</tr>
</tbody>
</table>

### RESULTS

**Characteristics**

The respondents in the qualitative study (n = 27) and the respondents in the quantitative study (n = 40 in the intervention group, n = 29 in the control group) broadly reflected the wider trial population in terms of age, gender, duration of diabetes, and glycaemic control except for the ethnicity of the participants. The intervention and control group also differed on ethnicity with regard to baseline characteristics, i.e. the intervention group included more participants from Dutch and Moroccan origin, and less participants from Surinamese origin (table 1).
Findings from the qualitative and quantitative study

In the qualitative interviews, the respondents not only reported on their medication adherence, physical activity and diet, but also on other aspects of self-management not included in the quantitative analyses, e.g. beverages and carbohydrates, and prevention/treatment of hypoglycemia.

Medication adherence

Both the intervention and control groups indicated that, after the intervention, they changed the way they took their medications (e.g. not on an empty stomach, not with milk). Most participants in the intervention group indicated that they now take their medications on time, which was confirmed by the group leaders.

Respondent: “I’ve learned to just be patient and calm and take your medicine on time, because sometimes I forgot to do that. Then I got a mobile phone ... You know, where I can set the time, so that I wake up in time in the mornings - and then eat something and take my medicines – And, if necessary, I go back to sleep again .. but then I have to keep this up, in the afternoons and the evenings.

Interviewer: So you just set the alarm?

Respondent: Yes, I put the alarm on – and now it all works OK.”

[Surinamese woman, 55 years: Intervention group 6]

Some participants indicated to now understand that medications should always be taken, not only when experiencing discomfort.

“I didn’t know how to use my medication, or maybe I didn’t read the leaflets - I don’t know, but it just wasn’t working. I was a bit .. well .. not that I denied it, I’ve never denied it. [...] But with the medication everything just took its own course ... I took my medicine whenever I thought about it - and whenever I didn’t feel good - because then I thought - you have to take your medication. If you’re feeling OK - you don’t need to take medicine, right? It’s like a headache - when you have a headache you think - I’m against taking medicine so I’m going to see how long I can stand it, and when the pain is too bad I’ll take a tablet - but then I delayed it for as long possible. And so I thought - with sugar, with metamorphine - you can also do that - but that was totally wrong.”

[Indonesian woman, 59 years: Intervention group 3]

The quantitative results indicate that at baseline, medication adherence was high in both groups. At 16 months, the intervention group continued their high adherence pattern, compared to a slight decrease in the control group (table 3).
Physical activity
The analyses show a greater and more diverse increase in physical activity in the intervention group. Most respondents in the intervention group reported to both walk and do sports more often since the intervention; this was confirmed by the group leaders.

“I've got three people, that's what I like - that we went to 'Movement for Elderly' (a neighborhood initiative) together and we do that every week now .. And they really like it and want to continue to support each other, so then the group carries on - without me.”
[Dutch group leader: Intervention group 7 and 8]

Respondent: “Then he (a group member) said – ‘Come on ladies we're going walking’ - I said damn that! At first we didn't like walking very much [...] because in the beginning I was going 'gasp ... gasp' - and then little by little, it just got better.”
Interviewer. Yes - you were getting better?
Respondent: Sure – we started walking even faster. “
[Ethnic Dutch woman, 62 years: Intervention group 1]

For most of these participants, doing sports was something they had never done before, whereas others increased the intensity of the sports they were already doing.

Respondent: The (health) is slightly better - thank God.
Interviewer: How?
Respondent: I feel good, so to speak. I had stopped doing a lot of things – like I said [...] Sports too, I do more sports, since K. (the group leader) said that it's good, I do more of it. I go to the gym, I have a yearly subscription. I went two ... three days and trained for one and a half hours - now I go five days a week.
[Moroccan man, 40 years: Intervention group 9]

The quantitative results indicate that at baseline, both groups were physically active for at least 30 minutes during about half of the week. After 10 months, the intervention group had significantly increased their physical activity whereas there was a decrease in the control group. The difference between the two groups was statistically significant (p=0.03).
Diet

Both groups indicated that they were eating more regularly since the intervention. They now eat more snacks in between meals and no longer eat late at night. The intervention group reported more diverse strategies for healthy eating than the control group. Only the intervention group seemed to plan ahead with regard to their blood glucose levels and adjusted their food intake accordingly (e.g. eat a low-carbohydrate snack to prevent their sugar level from being too high in the morning).

The qualitative study indicated that both groups attempted to eat less fat and sugar. However, the intervention group reported more diverse and more complex strategies to do so, e.g. replacing saturated fat with unsaturated fat, i.e. semi-skimmed milk instead of full-fat milk, 30+cheese instead of regular cheese and so on. Only the intervention group indicated to drink more water, less alcohol, and no soda, lemonade or fruit juice anymore. The group leaders of the intervention group confirmed that their participants had learned to eat healthier and make more deliberate choices regarding their food intake.

Respondent: “I’m someone who likes savory foods.”
Interviewer: “What do you really like to eat?”
Respondent: Sausage. Especially sausages made from horse meat - horse sausages are not so fatty (laughs) - that’s almost stopped now … but I.. have found it positive […]. I have the tendency to want to eat something in the evening.. a piece of cheese .. or ... it used to be crisps, nowadays it’s Japanese.. uh … those Japanese things.” [Dutch man, 68 years: Intervention group 2]

Other more complex strategies used only in the intervention group included choosing the most healthy alternative at a party, and planning ahead to avoid snacking.

“At the start of the course […] I’d go to work - and then I had such a craving for chips that I went out and bought chips. And that’s bad … So .. yeah .. that’s why I always have something in my bag, like a cracker or some fruit - then I’ve beaten it!”
[Surinamese woman, 56 years: Intervention group 2]

Further, only the intervention group used more diverse strategies to eat less carbohydrates and replaced products high in carbohydrates with products low in carbohydrates, e.g. replacing white rice with whole grain rice etc.
“Um, about brown rice, for example ... that it’s very good - and that it stimulates your intestines and all that. Because I suffer from constipation ... so I thought - OK then. And … what I didn’t know was that .. earlier - when you ate brown bread, brown bread is healthy... But it’s not brown bread that’s healthy, it’s whole grain bread.” [Surinamese woman, 64 years: Intervention group 6]

The quantitative analyses also indicated that both groups improved their diabetes specific diet. At baseline, both groups adhered to their diabetes-specific diet on 5 days of the week and improved their adherence at 10 and at 16 months. Fat consumption was low in both groups, mainly due to not eating full-fat dairy products or red meat 5 days a week. In both groups, fruit and vegetable consumption was high at baseline. Contrary to the qualitative analyses, at 16 months, fat consumption had improved in the control group only. In both groups, fruit and vegetable consumption had decreased at 16 months.

**Other aspects of self-management**
Both groups indicated that they were better able to recognize low blood glucose levels.
Respondent: And like the hypo - so what happens? How do you get it? I always thought it’s because you’re just not feeling good, no, well.. what I noticed is .. first I get really fast heart beats, and then I start sweating - and then I say .. oh.. I’m getting sick. I thought ‘Oh, I can feel my heart,’ but that’s not it - that was because the sugar was suddenly too low. “[…] And then it seemed like this … (acts as though she is having a heart attack)…

Interviewer: “Is there something wrong with your heart?”
Respondent: “No” (laughter).

[Dutch woman, 61 years: Intervention group 1]

However, only participants in the intervention group reported that they now also know how to deal with low blood glucose levels.

Respondent: Normally, you think .. oh yeah, just take .. what do you call it .. a dextro - take a dextran. Instead of… Then I think, but that’s not enough, because then you also have to eat something. And .. you know ... also how you should eat that food …

Interviewer: Oh yeah, so how do you that now? Because first you took a dextro - and then you didn’t do anything else?
Respondent: Well, I thought - now I’m not going to take anything any more… Although you have to eat something, and you have to drink ... Yes, that sort of thing - and I didn’t do that… stupid huh?

[Surinamese woman, 49 years: Intervention group 3]

Finally, they indicated that the intervention helped them to prioritize their diabetes, because they realize that they have to continue to ‘work hard’ for their diabetes. Acceptance of their diabetes as a chronic disease and therefore a continuous part of their lives, was part of this process.

“Diabetes means discipline. That’s what you know at a certain moment .. I just have to take certain steps - otherwise it’ll cost me my health. “[Dutch woman, 59 years: Intervention group 7]
TABLE 3. Effect of the intervention on self-management behaviours

<table>
<thead>
<tr>
<th></th>
<th>Medication adherence (days)</th>
<th>Intervention group (n=40) mean</th>
<th>Change compared to baseline (CI)</th>
<th>P-Value</th>
<th>Control group (n=29) mean</th>
<th>Difference in change compared to change intervention group</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline (mean)</td>
<td>6.95</td>
<td>6.97</td>
<td>0.93</td>
<td></td>
<td></td>
<td></td>
<td>0.93*</td>
</tr>
<tr>
<td>T1 (mean)</td>
<td>6.94</td>
<td>-0.01 (-0.32, 0.31)</td>
<td>0.96</td>
<td>6.84</td>
<td>-0.12 (-0.6, 0.37)</td>
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<tr>
<td>T2 (mean)</td>
<td>6.85</td>
<td>-0.10 (-0.42, 0.22)</td>
<td>0.53</td>
<td>6.58</td>
<td>-0.28 (-0.85, 0.29)</td>
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</tr>
<tr>
<td>Physical activity (days)</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Baseline (mean)</td>
<td>3.78</td>
<td>4.66</td>
<td>0.22*</td>
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<td></td>
</tr>
<tr>
<td>T1 (mean)</td>
<td>4.83</td>
<td>1.06 (0.26, 1.85)</td>
<td>0.01*</td>
<td>4.31</td>
<td>-1.41 (-2.64, -0.18)</td>
<td>0.03*</td>
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<tr>
<td>T2 (mean)</td>
<td>4.43</td>
<td>0.65 (-0.16, 1.46)</td>
<td>0.11</td>
<td>4.42</td>
<td>-0.89 (-2.37, 0.59)</td>
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<tr>
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<tr>
<td>Baseline (mean)</td>
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<td>5.26</td>
<td>0.82*</td>
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<tr>
<td>T1 (mean)</td>
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<td>0.40 (-0.42, 1.23)</td>
<td>0.33</td>
<td>5.53</td>
<td>-0.13 (-1.41, 1.15)</td>
<td>0.84</td>
<td></td>
</tr>
<tr>
<td>T2 (mean)</td>
<td>6.06</td>
<td>0.68 (-0.15, 1.51)</td>
<td>0.11</td>
<td>5.71</td>
<td>-0.23 (-1.74, 1.29)</td>
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</tr>
<tr>
<td>Fat consumption (days in which no full fat products or red meat was consumed)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Baseline (mean)</td>
<td>4.90</td>
<td>4.54</td>
<td>0.51*</td>
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<tr>
<td>T1 (mean)</td>
<td>5.55</td>
<td>0.65 (-0.30, 1.60)</td>
<td>0.18</td>
<td>4.48</td>
<td>-0.71 (-2.19, 0.78)</td>
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<td>T2 (mean)</td>
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<td>0.93</td>
<td>4.86</td>
<td>0.37 (-1.37, 2.11)</td>
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<tr>
<td>Fruit and vegetable consumption (days)</td>
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<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Baseline (mean)</td>
<td>5.18</td>
<td>5.79</td>
<td>0.26*</td>
<td></td>
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<td></td>
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<tr>
<td>T1 (mean)</td>
<td>5.32</td>
<td>5.31</td>
<td>0.14 (-0.68, 0.96)</td>
<td>0.74</td>
<td>-0.40 (-1.67, 0.86)</td>
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<tr>
<td>T2 (mean)</td>
<td>4.44</td>
<td>-0.74 (-1.57, 0.10)</td>
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<td>5.29</td>
<td>0.23 (-1.29, 1.76)</td>
<td>0.76</td>
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</tbody>
</table>

* Difference between intervention group and control group at baseline

DISCUSSION

The qualitative analyses showed that the intervention group better understood the rationale behind diabetes self-management and used more diverse and complex self-management strategies (thinking ahead, replacing foods with other more healthy alternatives) than the control group. They reported improvements in the ways they take their medications and are more physically active. Further, only the intervention group indicated to drink more water, less alcohol, and no soda, lemonade or fruit juice anymore and to use more diverse strategies to eat less carbohydrates. Finally, only the intervention group reported to be able to better handle changes in blood sugars and to prioritize their diabetes more.
The quantitative analyses confirmed the increase in physical activity only. Other aspects of self-management did not change (medication adherence), changed in the control group only (fat consumption) or changed in both groups (diabetes specific diet, fruit and vegetable consumption).

**Strength and weaknesses**

Ideally, we wanted to quantitatively evaluate the intervention and better understand the results using the qualitative data. Unfortunately, due to a small sample size and high dropout rates this was complicated. The qualitative data provide us with interesting insights on the effects, but provide no definite conclusions. Further validation of the results is required. Other studies confirming these results are necessary before the further implementation of *Powerful Together with Diabetes* can be justified.

Further, the respondents were interviewed right after the end of the intervention which gives no indication of long term intervention effects. Finally, the cultural groups that participated in the intervention were unequally represented in the qualitative study. Therefore these results cannot be generalized to all cultural groups in this study.

Unfortunately we were unable to collect HbA1c because it wasn’t measured regularly in the GP practices participating in this study. Grintsova et. al. also show that patients from socioeconomically deprived neighbourhoods receive less frequent measurements of HbA1c. To be able (as a researcher but also as a GP) to monitor the health status of socioeconomically deprived patients, this phenomenon need to be studied so attendance among this population in HbA1c measurements increases.

**Discussion of the results**

The intervention group showed more complex and more diverse self-management strategies, that were not observed in the comparison group. One of the distinctive features of *Powerful Together with Diabetes* is its focus on the social networks (social support and social influences) of the participants. Further, the intervention strategies were tailored to the educational needs of our target population.

Previous evaluations showed that the intervention increased emotional social support, diminished hindering social influences and increased the ability of participants to deal with peer pressure and temptations hindering self-management behaviours. Practising self-management with and encouragement from group members, walking together and energizers that created a pleasant atmosphere and
high levels of trust in the groups contributed to these changes. Also, participants named the fun and pleasant atmosphere as one of the reasons to keep participating in the intervention.

These effects on intermediate outcome measures might explain the effects on self-management behaviours. For example, actively involving (significant) others in self-management seems a successful intervention strategy. The participants regularly discussed and practiced the strategies they formulated in their action plans through role-playing exercises. Making an action plan with the help of others and practicing strategies together, probably helped participants to formulate realistic goals and strategies, to receive more social support for self-management and to feel more confident about implementing their action plan; these are important conditions for the action plan to be successful.

It also seems likely that the pleasant atmosphere in the groups and the high levels of trust facilitated learning among this population (being able to express opinions and ideas, asking questions) which might have contributed to the better understanding of the rationale behind diabetes self-management in the intervention group.

Finally, the participants were addressed as a group which might have made overcoming barriers to self-management behaviours easier. The quantitative analyses indicated that physical activity significantly improved in the intervention group. Low self-efficacy, poor health, fear of injury and a lack of access are known barriers for disadvantaged groups to be physically active. In our intervention, walking together in the neighborhood with the group was obligatory. Hesitant participants were stimulated by group members and group leaders to come along; in this way participants became acquainted with physical activity. It may also have made them aware that they can be physically active in their own neighborhood. They experienced improvements in theirs’ and others’ expenditure and being successful together; this probably increased their confidence about performing physical activity.

Conclusion
This study provides a starting point for future research on the effectiveness of this intervention. This study indicates that the intervention lead to a better understanding of the rationale behind diabetes self-management, to the use of more complex strategies in different situations in the intervention group and an increase in physical activity.
Once better studied, this intervention might be a promising starting point for diabetes education among socioeconomically deprived patients. Parts of this intervention could be introduced in regular diabetes care and might help socioeconomically deprived patients to achieve a basic understanding of diabetes and its management, and to involve their significant others in their self-management.

List of abbreviations
DISC (Diabetes in Social Context) Study
Diabetes self-management (DSM)
Powerful Together with Diabetes (PTWD)
Type 2 diabetes (TD2)
General practitioner (GP)
The Netherlands Organisation for Health Research and Development (ZonMw)
Intervention Group (IG)
Control Group (CG)
Academic Medical Centre (AMC)
Glycated hemoglobin (HbA1c)
The Summary of Diabetes Self-Care Activities Measure (SDSCA)

DECLARATIONS

Ethics approval and consent to participate
This study was approved by the Medical Ethics Committee of the Academic Medical Centre (AMC) in Amsterdam. Potential participants were invited to an information meeting after which they decided on participation and provided written or oral consent All qualitative interviews were audiotaped, with the respondents’ consent.

Consent for publication
Not applicable.

Availability of data and materials
Patient level data are available from the corresponding author. Informed consent for data sharing was not obtained but the presented data are anonymized and risk of identification is very low.

Declaration of competing interest
The authors declare to have no competing interests.
Funding
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Authors’ contributions
CV coordinated the study, and developed the intervention, constructed the design, and drafted the manuscript. VN developed the study, constructed the design, and revised the manuscript. I.G.M.V. drafted and revised the manuscript. G.N., PJMU and BJCM participated in the design of the study and revised the manuscript. KS developed the study, constructed the design, and revised the manuscript.

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REFERENCES


ADDENDUM 1

TOPIC LIST: PARTICIPANTS

1. How did you experience the intervention?
   a. Recruitment process?
   b. Group meetings?
   c. Meetings for significant others?
   d. Network meetings?
2. What did you like most? Why?
3. What did you like less? Why?
4. Would you recommend the intervention to other people?
5. Social network meetings?
   a. What was discussed?
   b. Experiences?
6. Meetings for significant others?
   a. How were significant others introduced?
   b. What was their reaction?
7. Group leader?

EXPERIENCED EFFECTS

1. What have you learned?
2. What effect do you think the intervention has had on you?
   a. On your diabetes? What? How did this happen?
   b. On your body? What? How did this happen?
   c. Diabetes self-management? What? How did this happen?
   d. Other things? What? How did this happen?
   e. Where do you think that comes from? What has contributed the most to this?
DEALING WITH DIFFICULT SITUATIONS

1. How did you deal with difficult situations before the intervention?
2. How do you deal with difficult situations now?
3. What do you think about these changes?
4. How do you think these changes occurred? How exactly did you learn that?
5. What could be improved about the way you deal with difficult situations?
6. What do you need for this?

CONTACT WITH GROUP MEMBERS

1. What sort of contact did you have with your group members?
   a. How did you experience this?
   b. What did you like/not like?
   c. Do you still see some of the people in your group?
2. Did you make friends during the intervention?
   a. With whom?
   b. How did that happen?
   c. What does this friendship involve?
   d. What activities do you do together for diabetes self-management (support, movement, eating)?
   e. Do you think you will continue to see each other in the future?
3. You did not make friends: why not? A need for friends? What do you need to make new friends?

FAMILY AND FRIENDS

1. Did your significant other participate in the intervention? What did they think about it?
2. How can you tell that they participated in the intervention?
3. How did they deal with your diabetes before they participated in the intervention?
4. How do they deal with your diabetes now?
5. How do they do that now? Has anything changed? How did this happen? What role did the intervention play?
ADDENDUM 2

TOPIC LIST: GROUP LEADERS

1. In general, how did you experience the intervention?
2. How did your participants do during the intervention (discussion of each participant)?
   a. Experiences
   b. Goals they worked on
   c. Changes in participants during the intervention
   d. Social interactions between participants
   e. Which participants did/did not benefit from the intervention and why
3. What was your role in creating the group feeling (adequately promoted? how?)
4. Did you feel that you had sufficient knowledge (e.g. own experience, training, and support from AMC) to carry out the intervention?
5. Experience with the manual (understandable? adequate/not adequate? what could be improved?)
6. Experience with the organization by AMC (availability of material, location, facilities)
7. Facilitators and barriers during implementation? How did you handle these? Do you think sufficient action was taken?
8. What were successful/ unsuccessful elements of the interventions? Why?
Recruitment and retention in a 10-month social network-based intervention promoting diabetes self-management in socioeconomically deprived patients: a qualitative process evaluation

Based on:


Accepted for publication in BMJ Open
ABSTRACT

Objectives

Socioeconomically deprived patients with type 2 diabetes often face challenges with self-management, resulting in more diabetes-related complications. However, these groups are often underrepresented in self-management interventions. Evidence on effective recruitment and retention strategies is growing, but lacking for intensive self-management interventions. This study aims to explore recruitment, retention and effective intervention strategies in a 10 month group based intervention among Dutch, Moroccan, Turkish and Surinamese patients from socioeconomically deprived neighbourhoods.

Methods

Participants were recruited through general practitioners and participated in a 10 month social network based intervention (10 groups, n = 69): Powerful Together with Diabetes. This intervention also targeted the significant others of participants and aimed to increase social support for self-management and to decrease social influences hindering self-management. A qualitative process evaluation was conducted. Retention was measured using log books kept by group leaders. Further, we conducted 17 in-depth interviews with participants (multi-ethnic sample) and 18 with group leaders. Interviews were transcribed, coded, and analysed using framework analyses.

Results

The general practitioner’s letter and reminder calls, an informational meeting, and the intervention’s informal nature facilitated recruitment. During the first months, the positive group atmosphere, the intervention’s perceived usefulness, opportunities to socialize, and a reduction in practical barriers facilitated retention. After the first months, conflicting responsibilities and changes in the intervention’s nature and planning hindered retention. Calls from group leaders and the prospect of a diploma helped participants overcome these barriers.

Conclusion

To promote retention in lengthy self-management interventions, it seems important that patients feel they are going on an outing to a social gathering that is enjoyable,
recreational, useful, and easy to attend. However, rewards and intensive personal recruitment and retention strategies remained necessary throughout the entire intervention period.

**Trial registration**: Dutch Trial Register NTR1886

**Strength and limitations of this study**
- Through its use of qualitative methods, this study provides us with an exploration of factors that affect recruitment for and retention during interventions according to participants.
- This study indicates what health promotors can do to recruit and retain participants for lengthy lifestyle interventions.
- We did not interview patients that refused participation or dropped out of the intervention. Asking these patients which factors facilitated or hindered recruitment and retention would have strengthened this study.
INTRODUCTION

Patients from socioeconomically deprived neighbourhoods are disproportionally affected by type 2 diabetes mellitus (Type 2 DM) and its related complications. Managing TD2 requires a number of extensive self-management behaviours regarding diet, medication adherence, physical activity, and often the monitoring of blood glucose levels. Complying with and maintaining such complex health regimens appears to be challenging, especially for socioeconomically deprived patients. Self-management interventions have been shown to be effective in improving metabolic control and health outcomes. However, in socioeconomically deprived groups, participation rates and retention rates are relatively low. Previous studies have emphasized that intervention studies targeting patients in lower socioeconomic groups need specific strategies to promote recruitment and retention.

Experimental studies have indicated that important factors affecting recruitment and retention in diabetes self-management (DSM) and other interventions are generally a lack of transportation, interference with responsibilities at home or in the community, lack of time, attitudes towards research affiliated with the intervention, financial costs, and burdensome procedures.

In addition, for ethnic minority and socioeconomically disadvantaged populations, specific barriers to recruitment and retention in these types of interventions are difficulties with maintaining participant contact, a lack of acceptability, feasibility, and cultural appropriateness to community values, distrust, other priorities of participants, practical barriers, having to take care of others, financial barriers, and a lack of child care.

Recent studies show that in order to improve recruitment, more intensive recruitment strategies are needed, as people in these groups appear to need more time and more face-to-face contact before they understand and support the intervention’s aim and the accompanying evaluation. The way an intervention is presented needs to be taken into account as well. Emphasizing the benefit for other similar patients and addressing patients’ concerns seem to be important to increase confidence regarding participation. In addition, an intervention might be made more appealing by emphasizing the practical exercises and group discussions rather than the more cognitive aspects (e.g. planning, reflection). There are indications that a GP referral might be a good strategy to convince those in lower socioeconomic groups to participate.
To improve retention, community and/or participant involvement is advised to ensure that the intervention is culturally appropriate and better tailored to the needs of the target population. Also, reducing practical and language barriers, cash incentives and building a relationship with participants seems to benefit retention. Further, multiple tracking, reminder and contact procedures are necessary. Finally, it seems important to take the composition of the intervention groups into account. It is important that participants not be too different from each other because this might cause misunderstandings or frighten people if they become aware of diabetes-related complications and problems they had no previous knowledge of.

In this paper we examine Powerful Together with Diabetes, a 10-month social network based intervention for patients with T2D from various ethnic origins living in socioeconomically deprived neighbourhoods in the Netherlands. The abovementioned studies often don’t distinguish between factors that affect the recruitment and retention for the intervention under study on the one hand, and the recruitment and retention for the accompanying study procedures on the other hand. In our study we will explicitly focus on the recruitment and retention from an intervention perspective. In addition, also the type of intervention we evaluate is interesting in view of the literature. More specifically, to our knowledge, little is known about effective recruitment and retention strategies for these kind of intensive lengthy diabetes self-management interventions among patients with type 2 diabetes living in socioeconomically deprived neighbourhoods.

During the development of Powerful Together with Diabetes, recruitment and retention played an important role, and specific methods and strategies were incorporated to facilitate this based on previous findings from the literature and theory. In this paper, we study which factors and/or intervention strategies facilitated or hindered recruitment and retention in Powerful Together with Diabetes according to the participants and their group leaders.

**METHOD**

**Setting and intervention**

The study was carried out in four cities in the Netherlands: Amsterdam, Utrecht, The Hague, and Zaandam. People with T2D who lived in socioeconomically deprived neighbourhoods in these cities were offered a 10-month social network-based intervention: Powerful Together with Diabetes. Neighbourhoods were selected using...
an official Dutch government ranking of socioeconomically deprived neighbourhoods. These neighbourhoods are characterized by lower-quality living conditions than those in other neighbourhoods due to an accumulation of problems: high unemployment rates, low income levels, high crime rates, deterioration, safety concerns, and a lack of relevant social networks and social contacts.

The intervention was specifically developed for patients from socioeconomically deprived neighbourhoods, and culturally targeted to the Turkish, Moroccan, and Surinamese patients in this group. The intervention was developed based on our formative research and different theories such as the theory of self-regulation, different self-management theories, and the transactional model of stress and coping, relapse prevention, and social learning theories. We further describe the development of the intervention elsewhere.

This intervention aimed to improve diabetes self-management by focusing on increasing social support for self-management among group members and significant others and by reducing social influences that hinder self-management. The entire programme lasted 10 months and consisted of 24 group meetings for the participants, 6 group meetings for their significant others, and 2 social network therapy sessions during which both participants and their significant others were present. There were two phases. Phase 1 (the first 13 meetings, months 1-3) focused on the basic tools needed to manage diabetes, such as creating positive outcome expectations, moral norms, increasing knowledge, skills and self-efficacy, facilitating social support, and recognizing and dealing with psychosocial mechanisms that hinder optimal DSM (such as peer pressure and existing social norms). Phase 2 (meetings 14-24, months 4-10) focused on putting the tools gathered in Phase 1 to use, developing and practising self-management skills until the participants had a solid set of coping skills that would enable them to optimally manage their diabetes in the long term.

Ten groups (5 ethnic Dutch (hereafter referred to as Dutch), 2 Turkish, 2 Moroccan, and 1 Surinamese group) with a total of 69 patients participated in the intervention from August 2010 through December 2011. The Turkish and Moroccan groups consisted of separate groups for men and women; both men and women were included in the Surinamese group. Each group was led by a group leader matched with the participants on ethnicity and gender. The group leaders were recruited through an advertisement, and selected based on their prior experiences with group-based education. The leaders of the Dutch groups were diabetes nurses, general practitio-
ners’ (GP) assistants, and nurse practitioners. The leaders of the Moroccan, Turkish, and Surinamese groups were lay health workers.

This intervention was evaluated in a trial that is described elsewhere\textsuperscript{22}. An experimental non randomized design with an intervention and a control group was used. The intervention was compared to standard group based diabetes education to be able to determine the additive value of actively intervening on social support, social influences and the immediate social environment of patients at the same time. The intervention group received \textit{Powerful Together with Diabetes}, the control group received \textit{Know Your Sugar} (see figure 1). This study has been approved by the Medical Ethics Committee of the Academic Medical Center (AMC) in Amsterdam, the Netherlands.

Previous evaluations indicated that this intervention seemed to increase social support and reduce social influences that hinder DSM for participants\textsuperscript{29}. An effect on the primary outcome (HbA1c and quality of life) could not be studied, as we were only able to recruit half of the required number of participants. We refer to a previous paper for a further explanation\textsuperscript{29}.

**Strategies to promote recruitment and retention**

We based our strategies to promote recruitment and retention on the literature and our needs assessment\textsuperscript{22}. To promote recruitment, informational meetings were organized to inform people about the intervention and answer their questions, and so increase support for and understanding of the intervention. To increase motivation, each patient received a letter from their GP inviting them to participate, and then two phone calls to remind them of the meeting. To encourage participation, we focused on the more practical aspects of the intervention (such as the specific content of the meetings) and helping other patients during the informational meeting rather than on the more cognitive elements (the behavioural goals of the intervention), and patients could also try out some of the activities. So they could understand what the intervention would be like, they exercised together and played a shortened version of the nutritional game, in which participants learn which dishes and foods they can eat as often as they like, and which dishes need to be eaten in limited quantities. Finally, only Phase 1 (the first 13 weeks) was emphasized to keep the intervention’s length from discouraging people. The meetings were held in the intervention location and the group leader was present so he or she could get acquainted with the participants.
Figure 1 Overview of the flow of the DISC study
To promote retention, practical barriers were reduced: the intervention was free of charge, within walking distance of participants’ homes, and the time and day were chosen by the participants and could be changed during the intervention. In cooperation with Turkish, Moroccan and Surinamese lay health advisors and Dutch diabetic nurses and GP assistants as well as by pretesting some intervention components the intervention was culturally targeted to the different groups. More specifically, the intervention was held in the mother tongue of the participants. In addition, we changed the outline of the intervention to make it compatible with the ethnic minority participants’ annual visits to their countries of origin and the celebration of Ramadan. We also culturally tailored the content of the intervention components to the different cultural groups, for example, by incorporating socio-cultural values and barriers to DSM, and adapting the materials to fit the needs of the different cultural groups.

Furthermore, matching the intervention groups on gender and ethnicity did not result in homogeneous groups, e.g. with regard to diabetes related complications. Therefore, we focused on mutual understanding instead. To increase mutual understanding, particular attention was paid to creating a pleasant atmosphere in the groups to facilitate group bonding and mutual trust. Strategies included providing tea and coffee, energizers, sharing news, exercising together, and paying attention to specific group rules (giving appropriate feedback, the confidence pact, communication), shared goals, and participatory problem solving.

Also, participants could obtain a diploma at the end of each phase when they took part in sufficient meetings. Finally, retention was promoted by making the intervention useful and interesting. Strategies included increasing relevance by adapting the intervention to the needs of participants by personalizing the intervention and giving the participants compliments. See table 1 for an overview of the goals and strategies for improving retention.
<table>
<thead>
<tr>
<th>General objective</th>
<th>Sub-goals</th>
<th>Intervention strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Participants keep participating during the intervention</td>
<td>Participants think the intervention suits them, that it’s important to participate and expect to benefit from participating in the intervention (outcome expectations, perceived norms, moral norms) Participants feel supported by their group members and their significant others to participate (self-efficacy, skills, social support) Participants are motivated to attend by other participants and their significant others (social influence)</td>
<td>Increasing relevance 1. Collection of questions: to guarantee that the meeting fits the needs of the participants, the group leaders start with a short description of the meeting and write down the participants’ questions on this topic. At the end of the meeting, the group leader checks whether all questions have been addressed. 2. Direct influence of participants on intervention strategies such as role-playing exercises and letter of the week (a fictional letter received from someone with diabetes who has a problem that needs to be solved. The participants are invited to brainstorm together about the problem and help solve the problem) so strategies can be adjusted by the group leader to their needs. 3. Personalizing the intervention: intervention focuses on the participant. E.g. participants were invited to ask their questions, to bring their own medications, to cook something for the group and got personalized feedback. 4. Summarizing results and complimenting participants: to help participants feel they have spent their time well, helped each other and have learned a lot, at the end of each meeting the group leader summarizes what the participants have learned. Group leaders also tell the participants how appreciative they are of all their achievements.</td>
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### TABLE 1. Overview of sub-goals and strategies of Powerful Together with Diabetes to improve retention (continued)

<table>
<thead>
<tr>
<th>General objective</th>
<th>Sub-goals</th>
<th>Intervention strategies</th>
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</table>
| 2. Participants experience the atmosphere in their group as pleasant and positive | Participants feel a connection with group members, expect to feel good after attending and have the feeling that their group members think it’s pleasant to see each other again (outcome expectations, perceived norms, moral norms)  
Participants are able to maintain a positive atmosphere in their group and are able to discuss inappropriate or unpleasant behaviour by group members together by giving each other positive feedback (self-efficacy, skills, social support)  
Participants stimulate each other to maintain a positive atmosphere in their group | Strategies to stimulate social support and group bonding  
1. Always tea and coffee present during the meetings and time to drink tea and coffee before the start of the intervention  
2. Energizers (intermezzi) during the intervention that last 5-10 minutes to stimulate bonding between group members. Examples: passing ball along and giving the person who receives the ball a compliment, playing ‘web of life’ (a game illustrating that we need each other), keeping a balloon up in the air together, etc.  
3. Participants share their positive news of the week with each other to get to know each other and to be more open to new information (self-affirmation). This news could be anything, as long as it was experienced as being positive by the participant.  
4. Rules for giving and receiving feedback: participants learn how to give appropriate feedback  
5. Exercising together: meant to get participants acquainted with physical activity but also to stimulate group bonding by making sure everyone mixed (opportunity to chat with person other than person next to you, interact with group leader) |
### Table 1. Overview of sub-goals and strategies of Powerful Together with Diabetes to improve retention (continued)

<table>
<thead>
<tr>
<th>General objective</th>
<th>Sub-goals</th>
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</tr>
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<tbody>
<tr>
<td>3. Participants think the meetings are fun and useful</td>
<td>Participants think the intervention suits them, that it’s important to participate and expect to benefit from participating in the intervention (outcome expectations, perceived norms, moral norms) Participants feel like they and their group members have learned new things after each meeting and feel like participating is part of their personal development (perceived cultural norms and moral norms)</td>
<td>Increasing relevance 1. Collection of questions: to guarantee that the meeting fits the needs of the participants, the group leaders start with a short description of the meeting and write down the participants’ questions on this topic. At the end of the meeting, the group leader checks whether all questions have been addressed. 2. Summarizing results and complimenting participants: To help participants feel they have spent their time well, helped each other and have learned a lot, at the end of each meeting the group leader summarizes what the participants have learned. Group leaders also tell the participants how appreciative they are of all their achievements. 3. Direct influence participants on intervention strategies such as role-playing exercises, letter of the week (a fictional letter received from someone with diabetes who has a problem that needs to be solved. The participants were invited to brainstorm together about the problem and help solve the problem)</td>
</tr>
<tr>
<td>General objective</td>
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<tr>
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<tr>
<td>4. Participants trust each other and feel safe with each other</td>
<td>Participants expect that they can trust their group members and that they are trusted by their group members despite hindrance from their significant others (outcome expectations, perceived norms, moral norms) Participants feel confident that they can trust their group members, feel supported to exchange confidential information and agree on appointments about the exchange of confidential information in their group (self-efficacy, social support, social influence)</td>
<td>Team building and human relations 1. Establishing shared goals and engendering commitment: exercises in which participants had to team up together but also shared goals to achieve as a group: a cookbook, getting both diplomas (Phase 1 and Phase 2), walking longer and further together each meeting Strategies to stimulate social support and group bonding 1. Creating non-judgemental small groups: making a confidentiality pact in the group (what is discussed in this group, stays in this group), rules for giving and receiving feedback (participants learn how to give appropriated feedback) but also rules about communication in the group (letting each other finish their sentences and listening to each other) 2. Forming coalitions/participatory problem solving: most intervention strategies included games in which the participants had to form coalitions, have group discussions or team up together to stimulate group bonding 3. Stimulate communication and mobilizing social support: participants share their positive news of the week with each other to get to know each other and to be more open to new information (self-affirmation), group leader regularly compliments the participants on the pleasant atmosphere</td>
</tr>
</tbody>
</table>
Study design of current study
The quasi-experimental trial was accompanied by a process evaluation. The process evaluation aimed to study the costs, the retention rate of the intervention, factors affecting recruitment and retention and the intervention fidelity. This paper reports on the retention rate and factors affecting recruitment and retention. These were studied using a mixed methods design using logbooks (quantitative data) and qualitative semi-structured interviews with participants and group leaders. The qualitative study was based on a phenomenological approach, which focuses on the subjective meaning of social action by trying to interpret people’s actions and their social world from their point of view. We conducted qualitative in-depth semi-structured interviews with participants (n = 17) and their group leaders (n = 9).

Recruitment of respondents
Our aim was to interview two participants per group. Because this was a hard-to-reach study population, we asked the group leaders to select and invite two respondents from their groups: participants who had been attending the intervention regularly and who had significant others who were also participating in the intervention.

In total, 17 participants from 8 intervention groups agreed to be interviewed (11 Dutch, 2 Turkish women, 2 Moroccan men, and 2 Surinamese). These respondents broadly reflected the wider trial population in terms of age, gender, duration of diabetes, and glycaemic control (see table 2). Four participants (the Moroccan women and the Turkish men) declined because they lacked the time, were on holiday, or felt they had already spent enough time on the study procedures (filling out questionnaires and having the physical examination). Response among group leaders (n = 9) was 100%. One participant unexpectedly brought another group member to the interview.

Data collection
A logbook was kept of the calls made to participants following the letter from their GP. To measure the retention rate, the group leaders kept a separate logbook in which they recorded the names of the participants (n = 69) present at each meeting. The interviews with the participants (n = 17) were conducted from September 2011 through January 2012 and lasted 40 to 60 minutes. To prevent memory bias, respondents were interviewed directly after the intervention ended. The interviews with the group leaders (n = 9) lasted approximately 60 to 90 minutes. They were interviewed once during and once directly after the intervention.
The recruitment and retention of participants

The interviews took place in the respondents’ first language either in their homes or in a community centre, if they preferred. The interviewers introduced themselves with little background information and emphasized they had no competing interest while conducting the interviews. They focused their introduction on wanting to evaluate the intervention and wanting to hear all (both positive and negative) experiences with the intervention. The interviews were audiotaped and transcribed with the respondents’ consent. The interviews were conducted by C.V. and M.J.E.K. (both researchers) with the help of an interpreter (Turkish interviews) or a Moroccan interviewer who had received training prior to the data collection. The Moroccan interviewer met the respondents before during other study procedures. The respondents met C.V. and M.J.E.K. during the observations in the intervention. Also, C.V. and M.J.E.K. had regular contact with the group leaders during the implementation of the intervention.

A topic guide was used during all of the interviews, and this was continually revised as new findings emerged. Relevant topics for participants included the recruitment process, experiences with the informational meeting, participation of significant others, and experiences with different parts of the intervention. Relevant topics for group leaders included participants’ progress during the intervention, facilitators and barriers during implementation, and successful and unsuccessful elements of the intervention (addendum 1 and 2). After the interview field notes were made to remember the setting and the impression the respondent made on the researcher.

Analysis

Retention rate was defined as the percentage of meetings attended in Phase 1 and Phase 2 respectively. Missing values were regarded as meetings participants did not attend. The last meeting of each phase consisted of a celebration during which participants would receive their diplomas, and because the group leaders did not take attendance during these meetings, they were excluded from the analyses (table 3).

The interviews with participants and their group leaders were coded and analysed with MAXQDA using framework analyses. A set of codes was developed based on previous research and the implemented intervention strategies during the intervention. After coding the interviews, these codes were grouped into categories. The interviews with the group leaders were used to check and consolidate the findings that emerged from the interviews with participants through data triangulation. After determining relevant patterns in the interviews with participants, we checked if these if we could confirm these patterns with the interviews of the group leaders.
RESULTS

Study population and retention

In general, the participants (n = 69) were predominantly female, were around 60 years of age, and had had diabetes for a longer period of time (table 2). 56.3% had an income of €454–€1906 per month, which is considered low in the Netherlands (in comparison, the minimum social benefit for a two person household is €1537 per month).

| TABLE 2. | Characteristics of respondents |
| --- | --- | --- |
| **Intervention group (n = 17)** | **Group leaders (n = 9)** |
| **Age (SD)** | 60.5 (7.86) | Unknown |
| **Gender** | Female 73.3% | 67% |
| **Total household income per month** | 18.8% | Unknown |
| €454–€1,270 | 37.5% | 31.3% |
| €1,270–€1,906 | 18.8% | 12.5% |
| More than €1,906 | 18.8% | 12.5% |
| Would rather not say | 18.8% | 12.5% |
| **Ethnicity** | Ethnic Dutch 47% | 44.5% (n = 4) |
| Surinamese | 23.5% | 11.1% (n = 1) |
| Turkish | 11.8% | 22.2% (n =2) |
| Moroccan | 11.8% | 22.2% (n =2) |
| Other | 5.9% | 0% |
| Missing | 0% | 0% |
| **Education** | No formal education/primary education 37.6% | 55.6% (n = 5) |
| Lower secondary vocational education (LBO) or preparatory secondary vocational education (VMBO) | 25% | 22.2% (n = 2) |
| **Profession** | Migrant health workers 55.6% (n = 5) | 55.6% (n = 5) |
| GP assistant | 22.2% (n = 2) | 22.2% (n = 2) |
| Nurse practitioner | 11.1% (n = 1) | 11.1% (n = 1) |
| Diabetes nurse | 11.1% (n = 1) | 11.1% (n = 1) |
| **How would you describe the state of your diabetes?** | Very good 33.3% | 33.3% |
| Good | 46.7% | 46.7% |
| Okay | 13.3% | 13.3% |
| Poor | 0% | 0% |
| Very poor | 0% | 0% |
| **HbA1c at baseline mmol/mol (SD)** | 60 mmol/mol 7.6% (0.63) | 60 mmol/mol 7.6% (0.63) |
| **Duration of diabetes in years (SD)** | 8.23 (6.2) | 8.23 (6.2) |
In Phase 1, 59.4% of the participants \((n = 69)\) were present at \(\geq 9\) meetings. In Phase 2, the corresponding percentage was 36.2%. Of the participants, 16% had one or more significant others who were present at \(\geq 4\) of the relevant meetings, and 39.1% of the participants were present at one or more social network meetings with one of their significant others. Although these significant others were predominantly husbands or wives \((n = 13)\), sometimes respondents invited a niece, an in-law, a daughter, or a neighbour \((n = 5)\) to the intervention as well. The respondents in the qualitative study \((n = 17)\) had higher retention in Phase 2 and the meetings for significant others than the overall study population (table 3).

<table>
<thead>
<tr>
<th>TABLE 3.</th>
<th>Retention Powerful Together with Diabetes</th>
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<tbody>
<tr>
<td>Retention among all participants in PTWD in % ((n = 69))</td>
<td>Retention among participants in qualitative sub-study in % ((n = 17))</td>
</tr>
<tr>
<td>Meetings Phase 1</td>
<td></td>
</tr>
<tr>
<td>All 12 meetings</td>
<td>13.0 ((n = 9))</td>
</tr>
<tr>
<td>9-11 meetings</td>
<td>46.4 ((n = 32))</td>
</tr>
<tr>
<td>6-8 meetings</td>
<td>24.6 ((n = 17))</td>
</tr>
<tr>
<td>0-5 meetings</td>
<td>16.0 ((n = 11))</td>
</tr>
<tr>
<td>Meetings Phase 2</td>
<td></td>
</tr>
<tr>
<td>All 10 meetings</td>
<td>10.1 ((n = 7))</td>
</tr>
<tr>
<td>8-9 meetings</td>
<td>26.1 ((n = 18))</td>
</tr>
<tr>
<td>6-7 meetings</td>
<td>14.5 ((n = 10))</td>
</tr>
<tr>
<td>0-5 meetings</td>
<td>49.3 ((n = 34))</td>
</tr>
<tr>
<td>Meetings for significant others</td>
<td></td>
</tr>
<tr>
<td>All 6 meetings</td>
<td>2.9 ((n = 2))</td>
</tr>
<tr>
<td>4-5 meetings</td>
<td>13.1 ((n = 9))</td>
</tr>
<tr>
<td>2-3 meetings</td>
<td>18.8 ((n = 13))</td>
</tr>
<tr>
<td>0-1 meeting</td>
<td>65.2 ((n = 45))</td>
</tr>
<tr>
<td>Social network therapy sessions</td>
<td></td>
</tr>
<tr>
<td>Both meetings</td>
<td>21.7 ((n = 15))</td>
</tr>
<tr>
<td>1 meeting</td>
<td>17.4 ((n = 12))</td>
</tr>
<tr>
<td>None</td>
<td>60.9 ((n = 42))</td>
</tr>
</tbody>
</table>

We describe the factors that affect recruitment of participants and their significant others, followed by the factors affecting retention according to the respondents \((n = 17)\) and the group leaders \((n = 9)\).

**Factors affecting recruitment of participants**

In short, important factors that affected recruitment were the GP letter, calling of the participants, participants’ attitude towards diabetes, the informal nature of the intervention, and the presence of other activities organised for the target population in the neighbourhood. The informational meeting seemed to play an important role in the recruitment as well.
The GP letter, calling of the participants, participants’ attitude towards diabetes, representation of the intervention, and other activities organised for the target population in the neighbourhood

After receiving a letter from their GPs, patients were called to remind them of the informational meeting. When they were called the first time (a week after receiving the letter), the majority had not yet opened or read it. During the second call (one or two days before the informational meeting), most patients needed to be reminded about the meeting or had some additional questions about the location or time.

Most respondents went to the informational meeting because they had a positive attitude towards diabetes, they thought diabetes was important and wanted to know more about it. Only the Dutch respondents mentioned that they went to the informational meeting because their GP had sent them a letter. The Moroccan group leaders indicated that a letter from the GP might convince Moroccan husbands to let their wives participate.

The informal nature of the intervention also seemed to influence people’s decision to participate. The Dutch group leaders said the participants had busy lives filled with family and work-related responsibilities that left almost no time for themselves. They indicated that the invitation provided participants with a legitimate excuse to get out of the house, meet other people, and create time for themselves.

Finally, the Moroccan group leaders indicated that Moroccan women are more likely to participate in interventions than Moroccan men because only a limited number of activities are organized specifically for them in the neighbourhood. In contrary, Moroccan men can often choose from multiple activities and tend to be more selective and to participate for reasons other than learning about diabetes.

When you say, ‘Yes, we’re going to come and give a class; they say things like, ‘Will there be coffee and tea? Will there be something to eat? Will we get something?’ See what I mean? Because that’s how some organizations do things, and that way, you spoil the target group. (Male Moroccan group leader)

The informational meeting

The informational meeting influenced the decision to participate as well. Most respondents enjoyed meeting the other participants and the group leader. After the informational meeting some respondents decided the intervention would be worthwhile. Other respondents and the group leaders said that the nutritional
The recruitment and retention of participants

game during the informational meeting made them more curious about diabetes and nutrition.

For everyone who came to our group, it was the informational meeting that got them there – everyone actually told me that they found out that peanut butter is a healthy sandwich spread. And that was such an eye-opener. ‘Well, then I should be able to learn even more.’ (Dutch group leader)

According to both group leaders and participants, the informational meeting’s focus on just the first phase of the intervention (three months) encouraged participation.

I heard that too: ‘If I’d known it was going to last 10 months, I never would have gone.’ (Dutch group leader)

Factors affecting recruitment of significant others

Participation by significant others in the meetings organized for them was rather low. The main factor affecting the recruitment of significant others was the willingness of participants to invite their significant others. They often did not want to burden their relatives, did not know who to invite, did not want relatives to meddle in their self-management or experienced feelings of shame which prevented them from inviting significant others.

To the extent that significant others participated, it was usually because they were asked to go.

He said, sure, I’ll go. That was on Monday evening then, if there was a meeting.
Yes. No, he didn’t mind. (Dutch woman)

Other respondents indicated they did not ask their significant others to participate because they did not want to bother them. The group leaders had different explanations for the participants’ hesitance to invite significant others: some participants had no social network and did not know who to invite, while others were hesitant to ask for help or did not want to burden their relatives. They needed extra guidance and encouragement from their group leader to do this. Further, some participants had shared so much information and intimate details about their marriages and daily lives with group members that this kept them from inviting their relatives.
They’ve talked so much about the group, themselves, and also about their partners that they’re a little hesitant to invite these people to family meetings…. You really know a lot. (Dutch group leader)

Finally, some participants were afraid their relatives would meddle with their diabetes management if they attended the family meetings. This was confirmed by the group leaders.

Because now of course they can do something from time to time and their partner won’t know if it’s right or wrong. But that would put an end to that. For example, there was one man who suddenly had to start going for a walk in the evening because his wife heard how good that was. Well, he didn’t like it one bit that I’d said that [laughter]. (Dutch group leader)

The Turkish, Moroccan, and Surinamese group leaders indicated that the participants in their groups simply did not want to have family meetings for close relatives (husbands and wives). They thought that shame might be an important reason. The female Turkish and male Moroccan group leaders said that especially the home visits during the intervention were a problem, which was why they decided to either have them in a community centre or not at all.

Because [when you visit them at home, ed.] everything’s out in the open. And even though they know me now, it’s still different [than family, ed.]. A stranger comes into your home and you see everything. How they live, their nice things and their awful things. And that can be painful. (Turkish female group leader).

Factors affecting retention in phase 1
As indicated above, 59.4% of the participants participated in almost all of the meetings in Phase 1; this was 36.2% in Phase 2. The factors that affected retention seemed to change over the course of the intervention. During the first months (phase 1), retention appeared to be fostered by the atmosphere in the group (created by the intervention length, the energizers, and by exercising together), the opportunity to socialize or get out of the house, experiencing the intervention as useful, and having practical barriers taken into account.

The atmosphere in the group
All participants emphasized how pleasant the atmosphere was in their group, which kept them participating or made participation easier. They enjoyed the social contacts with group members, the exchange of information and advice, and the
conversations that evolved. This was also the case for the relatives who attended the family meetings. Most group leaders emphasized that they felt like they had a special connection with their group and to know their group members very well.

Well, that’s the strange thing – at first I thought, wait a minute, like 24 times. But we all enjoyed it so much and had such a good time, you just don’t want to miss it. So as far as that goes, I didn’t think it was too long, no. (Dutch woman).

According to the group leaders, this can be explained by the length of the intervention that allowed participants to get to know each other very well and form attachments. Further, participants and group leaders often mentioned the energizers, which made the participants laugh and feel good about themselves (e.g. giving each other compliments), and exercising together.

The atmosphere was really good – we were always laughing. Because they would have a CD and you’d start to move and you know how that goes, it was really funny. For example, there was a woman sitting next to me, she’s over 80, and […] she said ‘I didn’t do any homework at all’. And then you really had to laugh. And one person […] we call her the ‘flying goalie’ (because she drives her mobility scooter so fast, ed.). Ha ha, yes, it’s a really nice group. (Surinamese woman, Dutch group)

Both respondents and group leaders said that exercising together was lots of fun and provided the participants with opportunities to chat with different people in their groups, which facilitated group bonding.

The opportunity to socialize or get out of the house

The intervention seemed especially attractive to people with limited social contacts. The possibility of socializing with others or getting out of the house appeared to encourage participants to attend all of the meetings. The Turkish women indicated they often feel lonely, and that the intervention provided them with the opportunity to meet up with people like themselves and make new friends. According to the Dutch respondents the intervention was an outing for them, which gave them something fun to do and somewhere to go.

I: Because you said you had to make an effort to go towards the end…. So what motivated you to keep showing up?
R: Well, to uh … I just kept going to uh … also because I uh, because you learned something from it. And also because you, what do you call it, well… it’s hard, but…
for me it was also an outing. […] Because it got me out of the house. Because I sometimes tend to stay inside. Then you got to go somewhere. (Dutch man)

A side effect of the positive atmosphere was that the majority of respondents indicated they did not like it when other group members stopped coming. This made them feel uncomfortable and ambivalent about their own participation. The group leaders confirmed that the absence of others made it almost impossible to motivate the remaining group members to keep attending.

**Experiencing the intervention as useful**

Almost all participants indicated they learned many new things during the intervention and that the intervention was very useful, which made them curious about other things they could learn. According to the respondents, this was also an important facilitator for the significant others. The majority of the participants said their relatives had enjoyed learning useful new things. The group leaders also indicated that most relatives saw the intervention as an eye-opener.

*My husband never says much. But what he does do is go straight for the peanut butter and also straight for the wine – wine had to be bought, peanut butter had to be bought. He didn’t touch his beer. Well, that’s quite something in itself, because usually my husband doesn’t let himself be influenced by anything at all.*

(Dutch woman)

**Having practical barriers taken into account**

Other facilitators for retention were the location of the community centre and the flexibility of the group leaders. Both participants and group leaders said they appreciated that the intervention location was within walking distance, making it easy to reach without having to pay for public transportation.

Both participants and group leaders mentioned flexibility as an important facilitator for retention. The Dutch participants and group leaders were satisfied that the energizers, content, and games could be adapted to their preferences, which kept them motivated. This was not mentioned in the Turkish, Moroccan, or Surinamese groups.

*Like when we played that game where we threw the string, those kinds of things. Then we would be like, really? It was kind of silly. We didn’t think it was such a big success, not as a group either…. ‘Come on, we’re not in nursery school!’ [laughter] Well of course, especially in the beginning, you want to be cooperative. But at a*
certain moment it was like, what do you think? Well, you know, we just talk it over, like we’re used to doing. (Dutch woman)

The Dutch participants also complimented the group leaders on being flexible when they were delayed or unable to come to a meeting. The group leaders confirmed that they changed the time and day, and also the time between meetings, to make it easier for group members to attend.

Sometimes I’m a little late, I call P. [group leader], sorry P., I’m still in the train.... Oh, no problem… see you in a bit. Things like that. Or if I had to work overtime, I’d say, well, next week you can let me know what you talked about, you can let me know (Dutch woman)

The Dutch group leaders also explained that they sometimes had to be flexible with the programme because of situations that needed special attention (e.g. the death of a participant) to keep participants from dropping out.

The Dutch group leader explains how she had to deal with an argument a participant and her husband (who showed up unexpectedly at the community centre) had in front of the other group members:

R: I thought, ‘Well, we’re not going to be able to get around to the purpose of tonight’s meeting [learning about diabetes, ed.].’ I have to deal with a problem, because otherwise she’s not going to come back – she [other participant] won’t dare show up again and…

Factors affecting retention in Phase 2

After the first months (phase 2), the length of the intervention meant that, conflicting responsibilities as well as changes in the nature of the intervention and its planning affected retention. Calling the participants and the prospect of receiving a diploma seemed to stimulate retention.

Conflicting responsibilities

Both group leaders and participants said they were also very busy with other things that needed their attention (things that were unexpected or could no longer be postponed), which made it harder to keep participating in both group and family meetings. In the Dutch groups, reasons for missing numerous meetings included appointments with others or with health professionals (participants often had multiple conditions), changes in work schedules, and illness (either becoming ill themselves or a spouse developing a chronic illness and needing care).
Yes, it was uh, almost a year. At a certain point it got to be a lot, because in the morning it was swimming. In the afternoon you went there to class. So, and I uh, also went to the general practitioner for my blood sugar. And you also had to go to the diabetes doctor, anyway, you had to go for your blood sugar, you had to go again and things like that. (Dutch man)

Among the Turkish men, reasons mentioned for longer absences were holidays in Turkey, changes in work schedules, problems with teenage children, and going abroad to arrange a marriage. Turkish and Moroccan women mentioned wedding preparations (arranging the dowry, planning the event), the month of Ramadan (having to do a lot of cooking), and holidays in Turkey. According to the Turkish and Moroccan group leaders, it is difficult to get in touch with the participants again after the holidays. Those in the Surinamese group mentioned holidays and having to leave suddenly for Suriname to take care of relatives there.

**Changes in the nature of the intervention and its planning**

In Phase 2 (meetings 14-24), the participants had to keep a diary, choose behavioural goals, and make action plans which they then had to put into practice in daily life. Both group leaders and participants indicated that Phase 2 was more difficult, more work, and less fun. This is reflected in the much lower retention rate in Phase 2, as indicated in table 3. In this phase, only one third of the participants managed to attend nearly all of the meetings. For some participants, Phase 2 meant they had to change behaviour they did not want to change.

And before that of course it was, ‘Oh, nice, we get to go to the meetings. We’ll learn something there.’ And then they’d come home and that would be that. And, well, sure, everyone has their own lives, don’t they, and taking care of the grandchildren, working, that not all of them feel like working on their goal too [in Phase 2]. (Dutch group leader)

Both group leaders and respondents from the Dutch groups said that because the meetings gradually became less frequent – going from once a week to once every two weeks and then to monthly – the meetings became harder to remember. When the meetings were weekly, it was easier to keep track of the day and time (because it was usually the same every week), and because there was less time between meetings, there was more regular contact with the group leader.
When participants were finding it hard to keep going to the meetings, they mentioned that getting a call from the group leader and their desire to receive both diplomas helped them to keep going.

**Calling the participants**

The Turkish, Moroccan, and Surinamese women all mentioned the group leader’s calls between meetings as a reason to keep participating in the intervention. This was confirmed by the leaders of the Turkish and Moroccan female groups and the Surinamese group. They said it was necessary to phone the participants between meetings throughout the entire intervention to hear how they were doing and to remind them of the upcoming meeting.

> Well, you know, I thought that what you’ve done till now was good. And calling people, you know, and that someone reminds you that you have to come to class…. Yes, every time, K. [group leader] just did it, time after time. (Surinamese woman).

In the Dutch groups, though, the participants asked the group leaders not to call between meetings because they felt this was unnecessary. The group leaders called only when someone was absent and to provide that participant with the information they missed; participants mentioned this as being a facilitator for participation. Calling did not seem to affect retention in the Turkish and Moroccan male groups. The Moroccan group leader said that participants often did not answer their phones, and that they often promised to come but then would not show up. The Turkish group leader said that when he called, participants would ask him about many other things (e.g. filling out a tax form). He would remind them about the intervention, but they would often forget to come.

**The diploma**

According to the group leaders, the diploma contributed to retention. During the interviews, participants would often show their diploma or mention that they had earned it without being prompted.

> They were incredibly proud of them [the diplomas]. Some of them framed it and are waiting for diploma number two…. [laughter] Because there are people in the group who’ve never had a diploma before in their life. (Dutch group leader)
DISCUSSION

When recruiting people from socioeconomically deprived neighbourhoods to participate in an intensive and lengthy self-management intervention, an invitation from the GP and calling the participants after sending a letter seemed important. Recruiting significant others proved to be more difficult, because of the resistance towards their participation among the participants: they did not want to bother their significant others, had no one to invite, or feared inviting them because of the personal matters they discussed during the intervention. Among Surinamese, Turkish and Moroccan participants, shame also seemed a barrier to invite significant others.

Factors influencing retention seemed to change over the course of the intervention. During the first months (phase 1), the positive atmosphere and the social contacts with group members seemed important. The intervention provided the participants with an outing or with the opportunity to socialize with people like themselves. Further, participants experienced the intervention as useful, and thought it was helpful that practical barriers were taken into account and adjustable to their preferences.

After the first months (phase 2), the length of the intervention made it more difficult for the participants to balance conflicting responsibilities. In addition, the nature of the intervention and its planning changed, which might have led to decreased motivation among participants. Phase 2 of the intervention was more difficult, more work, and less fun. Also, the meetings became less frequent, which made them harder to remember. Factors that helped participants overcome these difficulties were getting a call from the group leader and their desire to receive both diplomas.

Strengths and weaknesses

Through its use of qualitative methods, this study provides us with an exploration of factors that affect recruitment for and retention during interventions. It also explores intervention strategies that could contribute to optimizing recruitment and retention when implementing a lengthy self-management intervention. However, because no Turkish men or Moroccan women were included, the results cannot be generalized to all ethnic groups in this study.

Furthermore, patients that refused to participate or dropped out of the intervention were not included in this study because of ethical and practical constraints. Including also these patients would have strengthened this study.
Though this process evaluation shows that it is possible to motivate people to participate in a lengthy intensive self-management intervention, overall participation in the intervention was relatively low. Unfortunately we do not know the reasons for this, but this study indicates as well as other studies that an invitation alone is not enough, and that it is necessary to actively reach out to potential participants and encourage them to come.\textsuperscript{9,15,16} Future studies should take an intensive recruitment period into account and try to have a large pool of potential participants, for which we did not have the means, that can be invited.

**This study in relation to other studies**

The informational meeting seems to have helped convince patients to participate by showing them what they could expect, who the other group members would be, and what the intervention would be like in reality. Thoolen et al. also show that focusing on the practical exercises might make the intervention more appealing to this target population than focusing on what will be learned.\textsuperscript{9}

The pleasant atmosphere and the social interactions between group members and the group leader were important facilitators to retention. In this social network intervention, we paid a lot of attention to getting to know each other, facilitating group bonding, and the exchange of social support. A previous evaluation showed that the intervention increased social support among participants.\textsuperscript{29} It is likely that this social network component of the intervention, besides getting to know and understand each other, facilitated retention as well.

Other studies also report the importance of enjoying the intervention and the opportunity to participate in an activity or engage in meaningful social interactions.\textsuperscript{33-35} This might also explain why the second phase of the intervention, which was more difficult, affected retention. During this phase, participants were required to do homework and were asked to change behaviour they did not want to change, which might have meant they enjoyed it less. The energizers, the length of the intervention, and going on walks together contributed to the positive atmosphere and social interactions. However, those who continued to participate might also have been those with sufficient social skills to participate in a group intervention and who therefore benefitted more from these strategies.

This study shows that the decision to participate also depends on the desire to get out of the house, meet other people, and do something fun and recreational. People who live in socioeconomically deprived neighbourhoods, including those from ethnic minority groups, often have busy lives with multiple social roles to fulfil.
Although lack of time is often reported as a barrier to participation, this study indicates that this will not necessarily keep people from participating, and seeing the intervention as something that adds to their daily lives (something fun to do) might help people overcome this barrier. This indicates the importance of the enjoyable and social elements of health promotion programmes. When designing interventions these should not be overlooked.

The informational meeting also seemed to facilitate participation. Other studies have shown that a lack of awareness at the time of consent might facilitate drop-out because participants are not well informed and do not fully understand what participation entails and what is being asked of them. This meeting seemed to have increased curiosity about the intervention and to have enabled possible participants to get a clear picture of what the intervention would involve and what the other participants and the group leader would be like.

Adapting the intervention to the preferences of the participants (e.g. the content of the role-playing exercises) contributed to retention, something that has also been observed in other behaviour-related interventions. However, this was reported only by the Dutch respondents, which might have been due to the group leaders’ backgrounds. Adapting the intervention while maintaining the original goals is challenging, and requires a thorough knowledge of the intervention and its intended purpose. In the Dutch intervention group, the group leaders were diabetes nurses, nurse practitioners, and GPs’ assistants, whereas in the Turkish, Moroccan, and Surinamese groups they were migrant health workers. Migrant health workers are usually trained in group-based health education, whereas diabetes nurses, nurse practitioners, and GPs’ assistants have higher educational levels and may have more experience in using different strategies to help patients attain their goals. This underlines the importance of experienced staff to the success of a complex intervention like Powerful Together with Diabetes.

Also, monitoring participation and calling participants if they were absent or to remind them of the upcoming meeting was an effective retention strategy. We know from the interviews with the group leaders that keeping a diary or planning ahead was a challenge for the majority of participants. This could also explain the drop in retention in Phase 2, where the meetings were held at less regular intervals.

Finally, this study seems to indicate that some recruitment and retention strategies were more appropriate for certain subgroups than for others. E.g. a letter from the GP might convince Moroccan men to let their wives participate, while Moroccan
men tended to take other events and the conditions of the intervention (will there be food, what else am I receiving) into account when deciding upon their own participation. This might also be the case for the Turkish men, since both Moroccan and Turkish group leaders reported it was difficult to reach and convince participants to keep participating during the intervention and reported to be asked about a lot of other things during the intervention (e.g. filling out tax forms, difficulties with raising children) that had no relation with diabetes.

The intervention seemed especially attractive for people with limited social contacts. E.g. the intervention seemed to serve the needs of Turkish women, who reported a need to make new friends. On the other hand, in the Turkish, Moroccan and Surinamese groups we encountered feelings of shame towards people’s own social network, which affected the invitation of significant others and the organisation of home visits.

Also, though we made the intervention compatible with important cultural norms and practices (e.g. long holidays abroad in certain groups, month of Ramadan in Muslim groups) these still proved to be barriers to retention. For we did not take into account that these events, also need a lot of preparation, especially for the women. It therefore seems especially difficult to get in touch again with participants before and after these events. Only the Turkish and Moroccan women and the Surinamese respondents wanted to be called by the group leader throughout the whole intervention, which underlines the importance of the intensive retention strategies. Also, the Surinamese, Turkish and Moroccan groups more often reported unexpected family responsibilities as a barrier to retention (taking care of relatives abroad, arranging a marriage). These findings should be taken into account in future interventions.

In conclusion, an invitation from the GP followed by reminder calls seem necessary to motivate socioeconomically deprived T2D patients to go to an informational meeting in advance of a lengthy self-management intervention. This meeting also appears necessary to convince them to participate. Furthermore, to promote retention, it seems important that participants feel they are going on an outing to a social gathering that is enjoyable, recreational, useful, and easy to attend. However, rewards and intensive personal retention strategies remain necessary throughout the entire intervention period. Recruiting significant others appears to be more challenging, and seems to require the cooperation of the participants. Some recruitment and retention strategies seem more appropriate for certain groups, such as the GP letter, calling the participants, the informal nature of the intervention and
practical barriers that need to be taken into account. It is important to incorporate the above-mentioned recruitment and retention strategies into the intervention design, since these strategies require more time and financial resources, and create additional conditions for the layout of the intervention.

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**Contributorship statement**

CV coordinated the study, and developed the intervention, constructed the design, and drafted the manuscript. VN developed the study, constructed the design, and revised the manuscript. PJMU and BJCM participated in the design of the study and revised the manuscript. KS developed the study, constructed the design, and revised the manuscript.

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**COMPETING INTERESTS**

We have read and understood BMJ policy on declaration of interests and declare that we have no competing interests.

**DATA SHARING STATEMENT**

Patient level data (qualitative in depth interviews) are available from the corresponding author. Informed consent for data sharing was not obtained but the presented data are anonymized and risk of identification is very low.
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ADDENDUM 1

TOPIC LIST: PARTICIPANTS

1. How did you experience the intervention?
   a. Recruitment process?
   b. Informational meeting?
   c. Group meetings?
   d. Meetings for significant others?
   e. Network meetings?
2. What did you like most? Why?
3. What did you like less? Why?
4. Would you recommend the intervention to other people?
5. Social network meetings?
   a. What was discussed?
   b. Experiences?
6. Meetings for significant others?
   a. How were significant others introduced?
   b. What was their reaction?
7. Group leader?

EXPERIENCED EFFECTS

1. What have you learned?
2. What effect do you think the intervention has had on you?
   a. On your diabetes? What? How did this happen?
   b. On your body? What? How did this happen?
   c. Diabetes self-management? What? How did this happen?
   d. Other things? What? How did this happen?
   e. Where do you think that comes from? What has contributed the most to this?
DEALING WITH DIFFICULT SITUATIONS

1. How did you deal with difficult situations before the intervention?
2. How do you deal with difficult situations now?
3. What do you think about these changes?
4. How do you think these changes occurred? How exactly did you learn that?
5. What could be improved about the way you deal with difficult situations?
6. What do you need for this?

CONTACT WITH GROUP MEMBERS

1. What sort of contact did you have with your group members?
   a. How did you experience this?
   b. What did you like/not like?
   c. Do you still see some of the people in your group?
2. Did you make friends during the intervention?
   a. With whom?
   b. How did that happen?
   c. What does this friendship involve?
   d. What activities do you do together for diabetes self-management (support, movement, eating)?
   e. Do you think you will continue to see each other in the future?
3. You did not make friends: why not? A need for friends? What do you need to make new friends?

FAMILY AND FRIENDS

1. Did your significant other participate in the intervention? What did they think about it?
2. How can you tell that they participated in the intervention?
3. How did they deal with your diabetes before they participated in the intervention?
4. How do they deal with your diabetes now?
5. How do they do that now? Has anything changed? How did this happen? What role did the intervention play?
ADDENDUM 2

TOPIC LIST: GROUP LEADERS

1. In general, how did you experience the intervention?
2. How did your participants do during the intervention (discussion of each participant)?
   a. Experiences
   b. Goals they worked on
   c. Changes in participants during the intervention
   d. Social interactions between participants
   e. Which participants did/did not benefit from the intervention and why
3. What was your role in creating the group feeling (adequately promoted? how?)
4. Did you feel that you had sufficient knowledge (e.g. own experience, training, and support from AMC) to carry out the intervention?
5. Experience with the manual (understandable? adequate/not adequate? what could be improved?)
6. Experience with the organization by AMC (availability of material, location, facilities)
7. Facilitators and barriers during implementation? How did you handle these? Do you think sufficient action was taken?
8. What were successful/ unsuccessful elements of the interventions? Why?
General Discussion
GENERAL DISCUSSION

This thesis describes the development and evaluation of the process and effects of the intervention Powerful Together with Diabetes. This chapter contains a summary of the objectives of this study and how they relate to the main findings, an exploration of the study’s limitations, and a discussion of the implications for future research and interventions.

7.1 AIM AND MAIN RESULTS OF THIS THESIS

The aim of this project was to develop a theory- and evidence-based intervention with a focus on the social networks of people of Dutch, Surinamese, Turkish, and Moroccan origin who live in socioeconomically deprived neighbourhoods and have type 2 diabetes with suboptimal glycaemic control (haemoglobin A1C (HbA1c) > 53 mmol/mol). The intervention aimed to improve diabetes self-management (DSM) by increasing social support from significant others and peer patients with diabetes, and by diminishing social influences that hinder DSM such as peer pressure, social norms, and negative role models. We aimed to empirically test the intervention in an experimental design.

The intervention was developed according to the Intervention Mapping method (Chapter 2). We started with a needs assessment (an assessment of the health problem, its related behaviour, environmental conditions, and associated determinants) that focused on the role of social networks in self-management of type 2 diabetes. We found that patients from socioeconomically deprived neighbourhoods have social networks that seem less supportive of self-management because of their small size, their limited ability to acquire new information, and the strong social norms these social networks impose on their members which seem incongruent with self-management behaviours. Moreover, these patients receive little social support for self-management behaviours because there are often few sources of support present in their social networks, and they are hesitant to ask for such support or show others that they need this. These patients also find it difficult to deal with influences from their social network such as temptations, peer pressure, negative role models, and social norms. Often, the significant others do not seem to be aware that they can or should help, or do not know how to help. In addition, our needs assessment showed that interventions for patients from socioeconomically deprived neighbourhoods should also take the following into account: low outcome expectations regarding education and low motivation for education among participants;
a low priority for diabetes; a desire for practical information; reading and writing difficulties; and differences in knowledge about diabetes.

This information was used to develop Powerful Together with Diabetes (Chapter 2). In short, Powerful Together with Diabetes lasted 10 months and consisted of 32 meetings: i) 24 for participants (10 per group), ii) 6 for their significant others, and iii) 2 social network therapy sessions attended by the participants and their significant others. The intervention objectives were to get the participants to support and positively influence each other to better manage their diabetes, to effectively deal with social influences that hinder DSM, and to increase the engagement and support of significant others in DSM. Powerful Together with Diabetes was implemented in ten groups in Amsterdam Nieuw-West and Utrecht from August 2010 through December 2011.

The Powerful Together with Diabetes intervention was evaluated in a quasi-experimental study with a control group that received Know Your Sugar, a standard group-based educational intervention, and a second control group that received standard care. Know Your Sugar was a six-week group intervention that consisted of six group meetings for the participants. This intervention was based on standard diabetes education in the Netherlands, and was not specifically focused on the participants’ social networks. Know Your Sugar was implemented in nine groups in Zaandam, The Hague, and Amsterdam-Noord from January 2011 through November 2011.

We aimed to evaluate the effects of the intervention on HbA1c, quality of life, health-related outcome measures, DSM, and intermediate outcome measures. We evaluated the intervention both qualitatively and quantitatively at baseline and after 3, 10, and 16 months using a questionnaire, in-depth semi-structured interviews, and by collecting biomedical outcome measures from the participants’ medical files (Chapter 3).

The people who participated in this study were predominantly female, around 60 years of age, and had diabetes for 8 to 10 years. At the start of the intervention, they regarded the state of their diabetes as ‘okay’ to ‘very good’. Around 50% had no formal education, or primary education only. Two thirds had a total household income of less than €1,906 per month (the combined income of all household members after deducting taxes). As a comparison, in the Netherlands, the minimum social benefit for a two-person household is €1,537 per month. In general, the participants knew very little about diabetes and DSM – for example, although some participants had had diabetes for more than 10 years and used insulin, they did not know what
high or low blood glucose levels were or how to handle them. In addition to having diabetes, the participants in this study also experienced other difficulties in their daily lives. They often had multiple conditions, housing problems, spouses who were chronically ill and needed care, problems with teenage children, debts or very little money, and marital problems.

Based on an analysis of the qualitative data, we found that, immediately following the intervention (at 10 months), participation had led to a change in norms towards DSM, changes in DSM (improvements in the way they took medications, eating fewer carbohydrates and sweetened beverages, and an increase in physical activity), and an ongoing exchange of emotional support (Chapters 4 and 5). These changes were facilitated by intervention strategies such as practising self-management behaviours (e.g. taking walks together, practising refusing foods at a party) with encouragement from group members, and energizers that created a pleasant atmosphere and high levels of trust in the groups. The participants also seemed better prepared for and able to deal with social influences on self-management (e.g. having strategies ready for refusing food, or recognizing positive and negative influences on DSM). The skills learned through role-playing exercises, along with receiving feedback from group members and making an action plan with relatives, were intervention strategies that facilitated these changes. Also, relatives became more involved in DSM. Making an action plan together, having relatives participate in family meetings, and listening to group leaders contributed to these changes.

Based on the qualitative data, we carefully conclude that the intervention group seemed to better understand the rationale behind DSM (e.g. why blood sugar levels rise and what is needed to lower them, why changes in blood glucose cause diabetes-related complications, and why smoking is bad for more than just the lungs) and used more diverse and complex self-management strategies, such as thinking ahead (e.g. bringing a sandwich to keep from buying chips on the way home), replacing foods with other, healthier, alternatives (e.g. brown rather than white rice) than the control group (Chapter 5). In the quantitative analyses, we observed improvements in medication adherence and physical activity. Only the intervention group indicated they were drinking more water, less alcohol, had stopped drinking soda, other soft drinks, and fruit juices, and were using more diverse strategies to eat fewer carbohydrates. Finally, only the intervention group reported being better able to deal with changes in their blood sugar levels and giving their diabetes higher priority.
Finally, the qualitative analyses showed that important factors affecting recruitment were the invitation letter from the general practitioner (GP) and phoning potential participants after sending them the invitation letter (Chapter 6). Recruiting significant others was difficult because participants were hesitant to invite them. Overall retention of participants was low. In Phase 1, 59.4% of the participants (n = 69) attended ≥ 9 meetings. In Phase 2, the corresponding percentage was 36.2%. Of the participants, 16% had one or more significant others who attended ≥ 4 of the relevant meetings, and 39.1% of the participants attended one or more social network meetings with one of their significant others. During the first months (Phase 1), the positive atmosphere and social contacts with group members seemed important for the retention of participants. Participants also experienced the intervention as useful, thought it was helpful that practical barriers were taken into account, and appreciated that the intervention components could be adapted to their preferences. After the first months, the length of the intervention, conflicting responsibilities, and a change in the nature and planning of the intervention affected retention. Factors that stimulated retention were getting a call from the group leader and the diplomas.

7.2 RESULTS IN RELATION TO THE STUDY OBJECTIVES

Although this study has increased our insights into the effectiveness and feasibility of the intervention we developed, we should acknowledge that we were not able to achieve a number of our study objectives. More specifically, we were unable to report on long-term effects (at 16 months). We were also unable to report on the primary outcome measures (diabetes-related quality of life and HbA1c) or to compare our intervention with standard care. In addition, we were unable to report quantitatively on intermediate outcome measures such as social support and social influences. Finally, we could not report on the cost-effectiveness of the intervention because we were unable to study its effectiveness.

Problems with the implementation and the intervention’s effect evaluation were the main reasons for not being able to achieve all of our study objectives. The major themes were the recruitment and retention of participants, the collection of data from medical files, and the questionnaire we used for this study.

Recruitment and retention

First, recruitment of participants for the intervention study proved to be difficult, and retention of participants in the evaluation was low. Unfortunately, we do not
know the reason for the recruitment difficulties prior to the informational meeting. Factors complicating retention were the length of the intervention (which made it difficult to balance conflicting responsibilities), and the nature and planning of the intervention in phase 2. Recruiting significant others was difficult because participants were hesitant to invite them (chapter 6). This resulted in a small sample size, which limited our possibilities to quantitatively evaluate the intervention. Therefore, we were unable to measure the intervention's short and long-term effects on quality of life. We were also unable to optimally evaluate the effects of the intervention on other outcome measures such as medication adherence, physical activity, diet, and social support. This is not to say that it is impossible to recruit a large number of participants. In the next section, on lessons for future research, we will discuss how to do this.

Collecting data from medical files
During this study, we aimed to collect HbA1c and other biomedical outcome measures such as fasting glucose and lipids from the participants’ medical files. We also aimed to compare the HbA1c levels of our intervention and control groups with the HbA1c levels of a third control group that received no intervention at all. With the participants' consent, we asked their GP or GP assistant to send us this information. Unfortunately, we were unable to collect sufficient information on these outcome measures in both groups because they were not measured regularly in most of the GP practices that participated in this study. Although we do not know why the levels of these patients were not measured regularly in the participating practices, we do know this is a problem others have also encountered. Patients from socioeconomically deprived neighbourhoods seem to have their HbA1c levels measured less frequently than patients with a higher socioeconomic status. Therefore, we were unable to measure the effect of the intervention on the primary outcome measure HbA1c. This also made it impossible to compare the intervention with a group of patients that received standard care only. We were therefore unable to study the additional effects of a social network-based intervention by studying the differences in the effects on HbA1c of no intervention at all (standard care), providing patients with a group-based intervention (Know Your Sugar), and an intensive social network-based intervention (Powerful Together with Diabetes). Finally, because we could not measure the effects of the intervention on HbA1c, we were also unable to measure the intervention’s cost-effectiveness. In hindsight, we should have tested the availability of essential information in the medical files in a pilot study (see also the following section on lessons for future research).
Questionnaire

For this study, we examined existing questionnaires that had been pretested and evaluated in our target population. Because of the low literacy level of and limited knowledge of diabetes among our target population, we thought it was important to select questionnaires that could be easily understood. Therefore, if we could not find questionnaires that had been pretested in our target population, we tried to look for questionnaires that had been pretested in children. We selected the questionnaires with the best test results, and combined them to make the questionnaire for this study. Though we pretested this questionnaire in our target population before the start of the intervention, our evaluation showed that topics relevant to DSM were missing, such as the intake of alcohol and other beverages, how people take their medications, and recognizing and dealing with high and low blood glucose levels. Finally, during the interviews some of the respondents indicated they did not need to answer the questions on diet because they were not on a diet. It became clear that their perception of diet (a diet for losing weight) was different than what we had in mind for the questionnaire (a diet that takes diabetes into account).

In hindsight, during the pretesting of our questionnaire before the intervention, the respondents might not have known exactly what was meant by DSM as prescribed by their GP or diabetes nurse. For example, the respondents had been told by their GP or diabetes nurse that they had to lose weight, or take all of their medications, but often they did not know how to lose weight or exactly which medications they were supposed to take. This knowledge seems necessary to determine whether the questions on DSM are appropriate, and if there are also other aspects that are important but were not included in the questionnaire. In the next section (on future research), we will discuss possible solutions.

7.3 LESSONS FOR FUTURE RESEARCH

The limitations of this study show that the implementation conditions for the evaluation study should have been better identified before implementing and evaluating the intervention in a quasi-experimental trial. During our intervention development, we seem to have paid particular attention to Phase 1 (defining components of the intervention). In hindsight, we should also have paid more attention to Phase 2 (developing the optimum intervention and evaluation design). Important factors being studied in Phase 2 are the feasibility of delivering the intervention and the acceptability to providers and patients. We could have done this in a small pilot study with one intervention group. With this pilot study, we could have identified
important barriers to the recruitment and retention of participants. Although this thesis shows the importance of having a large pool of participants who can be invited to take part in an intervention, to prevent selection bias, it might be more important to devote further study to what would be needed to include the people who declined participation in this intervention and did not attend the informational meeting.

Second, we could have identified barriers to collecting data from the participants’ medical files. Based on these findings, researchers conducting future studies can decide whether it is possible to collect HbA1c data from medical files or whether they would prefer to do this by collecting their own data on HbA1c and other biomedical outcome measures.

Finally, the questionnaire could have been pretested in this pilot study. For the participants, answering questions about the questionnaire would have been less abstract if they could have based their answers on the intervention they just took part in. After a pilot study in which they learned about and practised DSM, they would probably have been better able to assess whether the questionnaire covered all relevant topics on DSM. We would also have been able to determine whether the questions had been asked in a way that prevented multiple interpretations among the respondents. With a questionnaire that covers all the relevant DSM topics, it would have been possible to better evaluate the effects of an intervention.

7.4 LESSONS LEARNED FOR FUTURE INTERVENTIONS

The results of this thesis raise questions about the way we developed Powerful Together with Diabetes, some promising intervention strategies, and future interventions for socioeconomically deprived patients. We will discuss these three topics here.

7.4.1 Development of the intervention according to Intervention Mapping

We developed the intervention according to the Intervention Mapping (IM) method. IM stresses the importance of conducting a needs assessment prior to developing the intervention. A health-related needs assessment includes a study of the determinants of behaviour and environmental contributors to health problems or health risks. Important elements of this method are the involvement of a planning group with planners, implementers, and programme participants, and the involvement of
the community throughout the whole project. Community involvement is needed to prevent a top-down, outsider approach\textsuperscript{167}.

IM thus advocates collaboration between community members and health professionals from the start of a project. Other researchers have also reported this to be a positive factor that helped in the development, adoption, and evaluation of an intervention\textsuperscript{8-11}. According to some studies, it can be difficult for health promoters to include the concerns and issues of the community because of the extra time needed for community involvement, and the often top-down organization of intervention development and top-down funding for these projects\textsuperscript{7,12}.

During our research project, we also experienced these limitations (a lack of time and top-down funding). When conducting our needs assessment, we performed all of the research activities as if we were developing a social network-based intervention for patients with suboptimal glycaemic control, as stipulated in our research grant proposal. This was the focus of the literature search, the interviews, the analyses of previously conducted interviews, and the diabetes forum. We did consult a panel of migrant health workers with Turkish, Moroccan, and Surinamese backgrounds multiple times. However, due to financial and time constraints, we did this fairly late in the process (after our needs assessment was completed) and asked for feedback only on topics related to our chosen focus, the social network.

Other factors complicated community involvement as well. We did not know the exact neighbourhoods in which the intervention would be implemented, and so where our participants would live (which community to address). Also, we planned to aim the intervention at a very specific target population (with suboptimal glycaemic control), and did not want to create false expectations within a community.

However, during the intervention we realized we did not know the full extent of the problems those in our target population faced in their daily lives. This thesis shows that getting to know this target population takes time. Because of the nature and long time span of the intervention, we got to know the participants and their daily lives very well. Although the social network appeared to be a real problem for their DSM, this target population also faces other important problems. During the intervention, we noticed it did not fully meet the participants’ needs, and did not seem entirely consistent with their daily lives.

Our participants often had multiple conditions, were experiencing financial problems, marital problems, domestic violence, or were caring for sick relatives. These
problems had a major impact on DSM, and the priority they gave to DSM. Although the intervention aimed to teach participants to deal with these problems so they could self-manage their diabetes, this was not always realistic. For example, if your husband or son is abusing you, it is very unlikely he will become a supportive partner in your DSM. Or if your wife is depressed and you have to take care of her, or if you have severe arthritis and are on the waiting list for an apartment with a lift and are currently unable to climb the stairs of your apartment building, it is unlikely you will start taking walks around the neighbourhood.

In hindsight, we conclude that the intervention could have been improved by investing more in participatory planning. If we had involved the target population and their community from the start, and asked them (with no predetermined focus) what they thought would be the best thing to do with regard to their diabetes, we might have come up with a different intervention, one with closer connections between the lives of our participants, the intervention, and the evaluation design.6 12 13

In some of the interventions that report positively on community involvement, the researchers involved the community before applying for funding. They chose the study design and applied for funding together with the community or based on the results gathered together with the community.8 11. Funding programmes are often clustered around specific themes or have a predetermined focus (e.g. ‘preventing overweight by influencing lifestyle factors’ or ‘Socioeconomic health disparities, prevention and reduction through integrated local policies’) that provide a research direction and might complicate involving communities without a predetermined vision.12 14 15

In hindsight, it would have been better not to decide beforehand what the nature of the intervention would be, but to decide this based on an open needs assessment together with the target population and their community. Funding organizations might facilitate this community involvement by allowing for a longer planning period, and by allowing great flexibility in the area of focus and topics that will be investigated in one project.12 16-18.

7.4.2 Promising intervention strategies
Though the intervention did not seem to meet all of the participants’ needs, this thesis shows that certain aspects seemed to work well in this target population. There are indications that some of the principles of this intervention seemed to work as intended. We will discuss the following principles and their the implications for
future interventions: an inductive educational approach, the use of non-traditional educational strategies, facilitating the group process, and a shared action plan.

**An inductive educational approach**

From our needs assessment, we knew that our target population seemed to have had few, or primarily negative, experiences with education. Therefore, we aimed to make learning as much fun and as interesting as possible. To make learning as much fun as possible, it was important that the participants did not feel like they were students, but nonetheless felt they were benefiting from each meeting. We tried to spark our participants’ curiosity about diabetes-related topics, and make participation a positive experience by focusing on their abilities rather than their shortcomings. One of our strategies was an inductive educational approach (active learning) to increase curiosity and satisfaction by only providing the information that participants wanted or needed. Instead of telling them what they needed to know from a theoretical point of view or ‘spoon-feeding’ information (deductive approach), we let participants practise with a problem they could relate to, and then slowly added information and theory to their understanding if they wanted this (inductive approach). An inductive approach, therefore, focuses on participants’ abilities and is closely connected to their interests.

From the evaluation, we learned that the participants were enthusiastic about, and often recalled, these elements of the intervention. The participants experienced the intervention as useful and interesting, which indicates there was indeed a close connection between the intervention and their interests. Moreover, by using this approach, the group leader could investigate what the participants already knew and also which knowledge was incorrect or new for participants, and so tailor their education accordingly. This is in concordance with other studies that show that inductive learning leads to more student involvement and activity in the classroom. It also leads to more retention of knowledge and improves skill development. These results suggest that inductive learning can be used as a method to gradually ease patients from lower socioeconomic groups into learning about DSM, and to explore their needs and interests for further health education.

**Use of non-traditional educational strategies**

From the needs assessment, we knew that traditional educational methods (where the teacher explains and the student listens) did not seem to be a good fit for this target population. Therefore, we used non-traditional educational strategies such as games and problem-solving (e.g. ‘letter of the week’), in which participants help a fictional person with diabetes) followed by role-playing and energizers (short
interactive intermezzos aimed at improving concentration and increasing group bonding). During every meeting the participants would go for a walk together to experience and practise taking walks in their own neighbourhoods. Finally, we paid a great deal of attention to using the newly acquired information and skills by practising these through role-playing exercises with guided feedback.

The evaluation showed that practising self-management with, and encouragement from, group members seemed to be important to changing norms towards self-management. The role-playing exercises and receiving feedback from group members seemed to be important to recognizing and preparing for social influences that hinder DSM. This is in line with a review which shows that interventions that use active, hands-on, participatory approaches are more effective among socially disadvantaged populations \(^2^4\).

**Facilitating the group process**

During this intervention, we aimed to use the group process between participants in various ways. First, we aimed to increase social support (including long term support) between the participants. Second, we aimed to facilitate learning through the interactions between group members. Finally, we aimed to facilitate retention through the group process. The needs assessment showed that it is important for interventions in this target population to consider how to shape and stimulate these group processes, since they may not evolve on their own.

We therefore decided to pay specific attention to facilitating the group process between participants. During the intervention, the participants were addressed as a learning group that would learn about diabetes together and would help each other understand and implement DSM during and after the intervention. To facilitate this process, the intervention strategies consisted of games and quizzes in which the participants would form alliances. Also, during the intervention, the participants established shared goals (e.g. making a cookbook) and were encouraged to share personal stories. The energizers during the intervention were aimed at getting to know each other, having fun together, and appreciating each other. Finally, group members first practised giving constructive feedback and giving and receiving social support with each other before actually doing this with group members and at home.

From the qualitative evaluation, we learned that as a result of these strategies, the participants got to know each other very well, and stayed in touch after the intervention had ended. They felt like a group (a club), and emphasized the mutual trust
and understanding. This positive atmosphere and the social contacts with other group members also seemed to be important to retention during the first phase, and contributed to a safe learning environment, which is known to contribute to how much and what students will learn.\(^{25}\)

This thesis shows that paying specific attention to group processes during an intervention seems to facilitate these processes in this target population. Retention of this target population in intervention studies is often difficult\(^{26-29}\), and a safe learning environment is important for effective adult learning\(^{30,31}\). The group process during the intervention seems to have positively influenced both domains, which suggests that these findings might also be useful for other group-based interventions.

**A shared action plan**

To involve significant others in DSM and make DSM a shared responsibility, the participants took part in two social network therapy sessions to draw up a shared action plan with their significant others. This plan was made during the first session, and revised in the second session if necessary. Most action plans were made by the participant and his or her spouse. The qualitative evaluation suggests that it was this action plan in particular that contributed to more attention being paid to DSM and more encouragement from and engagement of significant others in self-management behaviours. It was also beneficial in terms of recognizing and preparing for social influences that hinder DSM. It provided both the participants and their significant others with a shared vision on what needed to be done, and seemed to make it easier to make agreements with each other regarding DSM.

Studies have shown that the use of action plans in self-management education contributes to self-efficacy in changing behaviours\(^{32-34}\). Collective support, collective motivation, and collective responsibility were important elements for changing behaviour in couples in which one of the partners had diabetes\(^{35}\). In addition, poor communication and nagging about diabetes are known to be unhelpful in DSM\(^{36}\). The results show that shared action plans increased collective motivation and responsibility for DSM. This possibly improved communication and created clarity regarding DSM, and diminished social influences that hinder DSM. Though the efficacy of and conditions for (60% of the participants refused to make an action plan with their significant others) shared action plans need to be studied further, these results indicate that they could be an interesting tool that diabetes nurses and GP assistants could use to explore the support and influence of spouses on DSM, and to increase collective motivation and responsibility.
Some questions remain. We now know that engaging significant others through a shared action plan is important to increasing their role in self-management. However, we do not know how long these effects on social support, and the significant other’s role in DSM, will last. Moreover, attendance at the social network meetings was low because participants were resistant to inviting their significant others. The goal of increasing the engagement of significant others also forms the major barrier to the implementation of these meetings. These questions need to be answered before further implementation of these intervention strategies can be justified.

7.4.3 Considerations regarding future social network-based interventions

During this intervention, we aimed to improve DSM, which would in turn lead to improvements in diabetes-related quality of life and HbA1c. Although this thesis presents some successful intervention strategies, we should be realistic and also cautious in terms of the results we can expect in this target population.

First, following the intervention, the participants often felt they had made major changes to their DSM. For example, whereas before they may have never eaten fruit or exercised only rarely, now they indicated they were eating an apple a day or going on walks around the neighbourhood with a friend. Though the participants were satisfied with and proud of these changes, which might have had a positive influence on quality of life, it is unlikely that these kinds of modest changes will have a clinically relevant impact on HbA1c levels.

DSM interventions and psychological interventions seem promising with regard to psychosocial outcome measures in the general population. However, effects on metabolic control were mixed, the effects were primarily short-term ones, or the results on HbA1c were not significant. There are interventions that achieve clinically relevant outcomes in disadvantaged groups. Unfortunately, often only short-term outcomes have been observed, and the extent to which these results (among black and Hispanic populations in the United States) can be generalized to our target population is not known.

The participants in this intervention often lacked very basic knowledge and skills for DSM, even when they visited a diabetes nurse regularly. In addition, they often had many other problems in their lives that were related to their socioeconomic position, and these problems made it more complicated to give attention to DSM or put DSM into practice, as others have also shown. Although during the intervention we aimed to teach the participants to deal with barriers or problems related to...
their socioeconomic position, we also observed that this was not always realistic. It seems that we offered the participants an intervention that focused on only one of the symptoms (poor DSM) of their real problem (socioeconomic deprivation).

Given this arrearage, the nature of the changes these patients made after participating in an intervention that lasted nearly a year, and their multi-problem situations, it might be unreasonable to expect these patients to improve their DSM to an extent that will result in clinically relevant changes in metabolic control after just one intervention. Other outcome measures such as diabetes-related quality of life, self-efficacy, or diabetes-related distress might provide more insights into the possible benefits of this kind of intervention for these patients.

### 7.5 OVERALL CONCLUSION

*Powerful Together with Diabetes* contains promising intervention components, such as skills training and providing feedback using role-playing exercises, and involving significant others in self-management tasks by making a shared action plan. These seem to contribute to an increase in social support from significant others and peer patients, and a decrease in social influences from significant others that hinder DSM.

We also carefully conclude that the intervention improved certain aspects of DSM. Successful recruitment strategies were an invitation letter from the GP and phoning the participants after sending this letter.

Retention was stimulated through the positive atmosphere and social interactions between group members, taking practical barriers into account, and adapting the intervention to the participants’ preferences. The length, nature, and planning of the intervention formed barriers to retention after three months, while phoning participants and the diplomas helped to overcome these barriers.

This intervention seemed to have positively influenced social support, social influences, and some aspects of DSM, and also contains promising intervention strategies that seemed to work in this target population (such as an inductive educational approach, the use of non-traditional educational strategies, facilitating the group process, and a shared action plan). However, future interventions that focus on DSM in this target population should take into account the important lessons presented in this thesis.
For this target population, problems caused by socioeconomic deprivation seem to be a barrier to adequate DSM. For these patients, a decrease in the problems caused by socioeconomic deprivation could be a more effective and sustainable solution for making DSM less difficult. These patients might benefit more from interventions that focus on multiple life domains (such as housing, relationships, stress, work and income, and education) alongside targeted diabetes care, rather than interventions that focus on diabetes care alone. This is in concordance with other studies that have shown the value of social workers and referral to or close collaboration with social services in primary care for patients with complex health and social needs.\textsuperscript{48,49}
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Summary
Summary

Type 2 diabetes is a chronic disease that has a major impact on quality of life. This disease is becoming increasingly widespread, and disproportionally affects people who are socioeconomically deprived, including ethnic minorities. These patients often have more diabetes-related complications and higher diabetes-related mortality compared to patients in higher socioeconomic groups. Poorer glycaemic control, which is related to inadequate self-management behaviours, partially accounts for these increased risks. Complying with and maintaining the complex health regimen needed for diabetes – known as diabetes self-management (DSM) – seems to be challenging for these patients.

Difficulty with DSM is caused by multiple factors, including lack of knowledge, low health literacy, low risk perception, low outcome expectations, low self-efficacy and specific socioeconomic barriers. The social network (relatives and friends) also has a major impact on DSM through social support and social influences. Previous studies have shown that socioeconomically deprived patients receive less social support for self-management, and are often confronted with strong social influences from their immediate social environments that hinder self-management (e.g. peer pressure, specific cultural beliefs and expectations, and fewer positive role models).

Therefore, we aimed to develop an intervention, Powerful Together with Diabetes (PTWD), which targeted determinants that affect DSM, with a specific focus on stimulating social support for DSM and diminishing social influences that hinder DSM. This thesis describes the development and evaluation of PTWD, a 10-month social network-based intervention targeted to Dutch, Turkish, Moroccan, and Surinamese patients with type 2 diabetes living in socioeconomically deprived neighbourhoods.

In Chapter 2, we describe the development of PTWD, which we developed according to the Intervention Mapping method. Our needs assessment showed that patients from socioeconomically deprived neighbourhoods generally have social networks that seem less supportive of self-management because of their small size, their limited ability to acquire new information, and the strong social norms these networks impose on their members. Moreover, these patients receive little social support for self-management behaviours because they lack sources of support in their social networks, and are reluctant to ask for such support or show others they need it. These patients find it difficult to deal with influences from their social networks, such as various temptations, peer pressure, negative role models, and social norms. Moreover, the significant others of some of these patients are unaware
that they can or should help, or simply do not know how to help. Finally, the follow-
ing aspects should be taken into account during interventions for patients from
socioeconomically deprived neighbourhoods: low outcome expectations regard-
ing education combined with a low motivation for education among participants;
a low priority for diabetes; a desire for practical information; reading and writing
difficulties; and differences in knowledge about diabetes. Based on the needs as-
essment, we formulated the health-promoting behaviours for the social network
that would be achieved by participation in the intervention, and translated these
into performance objectives and change objectives. Finally, we selected theory-in-
formed intervention methods and practical strategies to produce the programme
components. This resulted in PTWD, a group intervention that lasted 10 months,
and consisted of 32 meetings: i) 24 for participants (10 per group); ii) 6 for their
significant others; and iii) 2 social network therapy sessions, which were attended
by the participants and their significant others.

Chapter 3 describes the study protocol used to evaluate the intervention. PTWD was
implemented in ten groups in Amsterdam Nieuw-West and Utrecht from August
2010 through December 2011. It was evaluated in a quasi-experimental study with
a control group that received Know Your Sugar, a six-week group intervention that
consisted of six group meetings for the participants. This intervention was based on
standard diabetes education in the Netherlands, and did not focus specifically on
the participants’ social networks. Know Your Sugar was implemented in nine groups
in Zaandam, The Hague, and Amsterdam-Noord from January 2011 through No-
vember 2011. We evaluated the intervention both qualitatively and quantitatively
at baseline and at 3, 10, and 16 months through a questionnaire, in-depth semi-
structured interviews, and by collecting biomedical outcome measures from the
participants’ medical files.

In Chapter 4, we examined whether the intervention had resulted in changes to
social support and social influences, and if so, which elements of the intervention
had contributed to this. The intervention led to a change in norms towards self-
management, changes in self-management itself, and an ongoing exchange of
emotional support. These changes were facilitated by practising self-management
with and encouragement from group members, taking walks together, and energiz-
ers that created a pleasant atmosphere and high levels of trust in the groups. The
participants also seemed better prepared for and able to deal with social influences
on self-management. The skills learned through role-playing exercises, along with
receiving feedback from group members and making an action plan with relatives,
made these changes easier to make. Also, relatives became more involved in self-
management. Making an action plan together, having relatives participate in family meetings, and listening to group leaders contributed to these changes.

In Chapter 5, we used a mixed-methods approach to examine the effects of the intervention on DSM (medication adherence, physical activity, and diet). Based on qualitative data, we carefully concluded that the intervention group seemed to better understand the rationale behind DSM and used more diverse and complex self-management strategies (thinking ahead, replacing foods with other, healthier, alternatives) than the control group. In the quantitative analyses, we observed improvements in medication adherence and physical activity. Only the intervention group indicated they were drinking more water, less alcohol, had stopped drinking soda, other soft drinks, and fruit juices, and were using more diverse strategies to eat fewer carbohydrates. Finally, only the intervention group reported being better able to deal with changes in their blood sugar levels and giving their diabetes higher priority.

In Chapter 6, we used a qualitative study to examine factors affecting recruitment and retention of participants in this intervention. Factors that were important to recruitment were an invitation letter from the GP and phoning the participants after sending this invitation letter. Recruiting significant others was difficult because participants were hesitant to invite them. During the first months (Phase 1), the positive atmosphere and social contacts with group members seemed important. Participants also experienced the intervention as useful, and thought it was helpful that practical barriers were taken into account and could be adapted to their preferences. After the first months, the length of the intervention, conflicting responsibilities, and a change in the nature and planning of the intervention affected retention. Factors that stimulated retention were getting a call from the group leader and the diplomas.

In Chapter 7, the general discussion, we summarize the most important findings and discuss methodological considerations and the implications of this thesis for health promotion among socioeconomically deprived patients.

PTWD contains promising intervention components, such as skills training, providing feedback using role-playing exercises, and involving significant others in self-management tasks by making a shared action plan. These seem to contribute to an increase in social support from significant others and peer patients, and a decrease in social influences from significant others that hinder DSM.
Summary

We also carefully conclude that the intervention improved certain aspects of DSM, such as a better understanding of the rationale behind DSM, the use of more complex self-management strategies, and an increase in physical activity, but we could not quantitatively confirm these findings. Successful recruitment strategies were an invitation letter from the GP and phoning the participants after sending the invitation letter.

Retention was stimulated through the positive atmosphere and social interactions between group members, taking practical barriers into account, and adapting the intervention to the participants’ preferences. The length, nature, and planning of the intervention formed barriers to retention after three months, while phoning participants and the diplomas helped to overcome these barriers.

A number of the study objectives could not be realised due to problems with recruitment and retention of participants, collecting data from medical files, and the questionnaire we used for this study. We conclude that, during the intervention’s development, we should have paid more attention to the feasibility of delivering the intervention and to the intervention’s acceptability to providers and patients. By conducting a small pilot study, we could have identified important barriers to the recruitment and retention of participants and to the collection of data from participants’ medical files, and could have pretested the questionnaire more thoroughly.

Finally, there are lessons to be learned from this thesis in terms of future health promotion in this target population. First, although the intervention was appreciated and experienced as useful, we noticed that the intervention did not fully meet the needs of the participants, and did not seem to be entirely consistent with their daily lives. Our participants often had multiple conditions, were experiencing financial problems, marital problems, domestic violence, or were caring for sick relatives, and these problems had a major impact on DSM. Although the intervention aimed to teach participants to deal with these problems so they could self-manage their diabetes, this was not always realistic. In hindsight, we would conclude that the intervention could have been improved by investing more in participatory planning. Rather than deciding beforehand that the intervention should focus on the social network, it would have been better if we had based our decision on an open needs assessment together with the target population and their community.

Second, we found a number of successful intervention strategies that might be useful for future interventions. These include an inductive educational approach, the use of non-traditional educational strategies, facilitating the group process, and
a shared action plan that seemed to work well in this target population. However, there are some questions that need to be answered before further implementation of these intervention strategies can be justified.

Third, although this thesis reveals some successful intervention strategies, we should be realistic in terms of the results we can expect in this target population. Based on the findings of this thesis and the insights gained regarding this population, it might be unreasonable to expect these patients to improve their DSM to an extent that will result in clinically relevant changes in metabolic control after just one intervention. We hypothesize that, for these populations, a decrease in the problems caused by socioeconomic deprivation could be a more effective and sustainable solution for making DSM less difficult. These patients might benefit more from interventions that focus on multiple life domains (such as housing, relationships, stress, work and income, and education) alongside targeted diabetes care, rather than interventions that focus on diabetes care alone.

Finally, we conclude that this intervention might have positively influenced social support, social influences, and some aspects of DSM, and also contains promising intervention strategies that seemed to work in this target population. Future interventions focusing on DSM in this target population should carefully consider what effects they expect to achieve in this population, and adjust their research designs accordingly. Also, this target population might benefit more from an approach that goes beyond DSM by actively involving them in the intervention and evaluation design, and by asking them about the problems that need to be addressed before DSM can be attained.
Samenvatting
SAMENVATTING

Type 2 diabetes (hierna: diabetes) is een chronische aandoening met een ongunstige invloed op de kwaliteit van leven van patiënten. De prevalentie van diabetes neemt toe en treft vooral mensen uit lagere welstandsgroepen, waaronder personen met een niet Nederlandse achtergrond. Deze patiënten hebben vaak meer diabetes gerelateerde complicaties en een hogere diabetes gerelateerde sterfte dan patiënten uit hogere welstandsgroepen. Een slechtere glykemische instelling, gerelateerd aan minder adequaat diabetes zelfmanagement, vormt één van de oorzaken voor deze verhoogde risico's. Het voldoen aan en het volhouden van het complexe gezondheidsregime dat hoort bij diabetes, ook bekend als diabetes zelfmanagement, vormt een uitdaging voor deze patiënten.

Meerdere determinanten dragen bij aan de problemen die deze patiënten ondervinden met diabetes zelfmanagement zoals een gebrek aan kennis, lage gezondheidsvaardigheden, een lage risicoperceptie, lage uitkomstverwachtingen, weinig eigen effectiviteit en specifieke sociaaleconomische barrières (bijvoorbeeld het niet kunnen betalen van strips voor de glucosemeter). Daarnaast heeft het sociale netwerk (familieleden en vrienden) ook invloed op diabetes zelfmanagement door het al dan niet geven van sociale steun. Eerder onderzoek heeft aangetoond dat patiënten in lage welstandsgroepen minder sociale steun ontvangen, steun die nodig is om het diabetesregime vol te houden. Bovendien worden zij geconfronteerd met sociale invloeden die diabetes zelfmanagement belemmeren (bijvoorbeeld groepsdruk, bepaalde culturele waarden en normen en minder positieve rolmodellen).

Het doel van dit project was het ontwikkelen van een interventie, Samen sterk met suiker. Het doel van deze interventie was het verbeteren van diabetes zelfmanagement door middel van het stimuleren van sociale steun voor diabetes zelfmanagement en het verminderen van sociale invloeden die diabetes zelfmanagement belemmeren. Dit proefschrift beschrijft de ontwikkeling en evaluatie van Samen sterk met suiker: een sociale netwerk interventie met een duur van 10 maanden gericht op diabetes patiënten met een Nederlandse, Turkse, Marokkaanse en Surinaamse achtergrond uit lage welstandsgroepen.

In hoofdstuk 2 beschrijven wij de ontwikkeling van Samen sterk met suiker volgens de methode 'Intervention Mapping'. Intervention Mapping is een methode om problemen rondom gezondheidsgedrag te identificeren en daar oplossingen voor te formuleren. De behoefteanalyse die vooraf ging aan de interventie ontwikkeling laat zien dat patiënten uit lage welstandsgroepen minder gunstige sociale
Samenvatting

Netwerken hebben voor diabetes zelfmanagement vanwege de beperkte omvang, de beperkte toegankelijkheid tot nieuwe informatie en de sociale normen die deze netwerken kenmerken. Daarnaast ontvangen deze patiënten weinig sociale steun voor diabetes zelfmanagement omdat zij minder bronnen van steun in hun sociale netwerken hebben en niet bereid zijn hulp te vragen of anderen te laten zien dat zij die ondersteuning nodig hebben. Ook vinden deze patiënten het moeilijk om adequaat om te gaan met sociale invloeden van anderen zoals verleidingen voor ongezond gezondheidsgedrag, groepsdruk, negatieve rolmodellen en sociale normen. Familie en vrienden zijn zich er niet van bewust dat zij steun kunnen of moeten bieden bij diabetes zelfmanagement of weten niet hoe zij de diabetespatiënt kunnen ondersteunen. Tot slot bleek uit onze behoefteanalyse dat tijdens interventies voor diabetes patiënten uit lage welstandsgroepen rekening gehouden moet worden met de volgende aspecten: lage uitkomstverwachtingen met betrekking tot educatie en een lage motivatie voor educatie onder deze doelgroep, een lage prioriteit voor diabetes zelfmanagement, de behoefte aan met name praktische informatie, beperkte lees- en schrijfvaardigheden en verschillen in kennis over diabetes.

Op basis van de behoefteanalyse hebben wij gezondheidsbevorderende gedragingen voor het sociale netwerk, die zouden moeten worden bereikt met de interventie, geformuleerd. Deze zijn vervolgens vertaald naar performance (gedragsdoelen) en change objectives (doelen voor de determinanten die van invloed zijn op de gedragsdoelen). Tot slot hebben wij theoretische interventiemethoden en -strategieën geselecteerd om programmacomponenten te maken. Dit heeft geresulteerd in Samen sterk met suiker, een groepsinterventie die 10 maanden duurde en bestond uit 32 bijeenkomsten: i) 24 bijeenkomsten voor de deelnemers (10 per groep), ii) zes bijeenkomsten voor familie en vrienden, en iii) twee sociale netwerk bijeenkomsten waarbij zowel de deelnemer als maximaal twee van zijn/haar vrienden en familieleden aanwezig waren.

Hoofdstuk 3 beschrijft het onderzoeksprotocol dat wij gebruikt hebben om de interventie te evalueren. Van augustus 2010 tot december 2011 zijn er 10 groepen Samen sterk met suiker geïmplementeerd in Amsterdam Nieuw-West en Utrecht. De interventie werd geëvalueerd door middel van een quasi-experimentele studie met een controlegroep die deelnam aan Ken uw suiker, een groepsinterventie van zes bijeenkomsten met een duur van zes weken. Deze interventie was gebaseerd op standaard diabeteseducatie in Nederland en had geen specifieke focus op het sociale netwerk van de deelnemers. Van januari 2011 tot november 2011 zijn er negen groepen Ken uw Suiker geïmplementeerd in Zaandam, Den Haag en Amsterdam Noord. Beide interventies zijn zowel kwalitatief als kwantitatief geëvalueerd op
Samenvatting

baseline en na 3, 10 en 16 maanden door middel van een vragenlijst, semigestructu-
reerde diepte-interviews en door het verzamelen van biomedische uitkomstmaten
uit de medische dossiers van de deelnemers.

In hoofdstuk 4 beschrijven wij hoe de interventie sociale steun voor en sociale invloe-
den op diabetes zelfmanagement veranderd heeft en welke interventie strategieën
hieraan bijgedragen hebben. Wij vonden dat de interventie heeft bijgedragen aan
een verandering in sociale normen met betrekking tot diabetes zelfmanagement,
een verandering in diabetes zelfmanagement zelf en de langdurige uitwisseling van
emotionele ondersteuning. Het oefenen van zelfmanagement samen met groepsgenoten,
de aanmoedigingen van groepsgenoten, het samen wandelen en de energizers,
die bijdroegen aan een prettige sfeer en onderling vertrouwen tussen de
deelnemers, droegen bij aan deze veranderingen. Daarnaast leken de deelnemers
beter voorbereid op de negatieve sociale invloeden op diabetes zelfmanagement
en wisten zij hier na de interventie beter mee om te gaan. De vaardigheden, geleerd
tijdens de rollenspellen, maar ook het ontvangen van feedback van groepsgenoten
en het gezamenlijke actieplan met familieleden droegen bij aan deze veranderin-
gen. Tot slot waren familieleden na de interventie meer betrokken bij het diabetes
zelfmanagement. Het maken van een gezamenlijk actieplan, het deelnemen aan
de familiebijeenkomsten en het luisteren naar de groepsbegeleiders droeg bij aan
these veranderingen.

In hoofdstuk 5 hebben wij het effect van de interventie op diabetes zelfmanage-
ment (medicatietrouw, lichaamsbeweging en voeding) bestudeerd met een combi-
natie van kwalitatief en kwantitatief onderzoek. Op basis van de kwalitatieve data
concluderen wij voorzichtig dat de interventiegroep de rationele achter diabetes
zelfmanagement beter begreep en meer diverse en complexe zelfmanagement
strategieën gebruikte (zoals vooruit denken, voedingsproducten vervangen door
gezondere alternatieven) dan de controlegroep. De kwantitatieve data laat verbe-
teringen in medicatietrouw en lichaamsbeweging zien. Alleen de interventiegroep
gaf aan meer water te drinken, minder alcohol en geen frisdrank, limonade of vruch-
tensap meer te drinken. Ook gebruikten zij meer diverse strategieën om minder
koolhydraten te eten. Tot slot gaf alleen de interventiegroep aan dat zij beter om
kunnen gaan met schommelingen in hun bloedsuikers en meer prioriteit te geven
aan hun diabetes.

In hoofdstuk 6 hebben wij factoren die van invloed zijn op het werven en behouden
van deelnemers in de interventie bestudeerd. Belangrijke factoren van invloed op
de werving van deelnemers waren een uitnodiging van de huisarts en het bellen
Samenvatting

van mogelijke deelnemers na het sturen van deze uitnodiging. Het werven van familieleden en vrienden werd bemoeilijkt doordat deelnemers moeilijk over te halen waren om deze mensen uit te nodigen. Tijdens de eerste drie maanden van de interventie leek met name de positieve gezellige sfeer in de groep van invloed op het behoud van de deelnemers. Daarnaast ervoeren de deelnemers de interventie als nuttig en gaven zij aan dat het rekening houden met praktische belemmeringen en het aanpassen van de interventie aan hun voorkeuren bijdroeg aan het blijven deelnemen. Na de eerste drie maanden, waren de lengte van de interventie, tegenstrijdige verantwoordelijkheden en verandering in de aard en de planning van de interventie van invloed op het behoud van deelnemers in de interventie. Factoren die bijdroegen aan het behoud van deelnemers waren het bellen van de deelnemers en het vooruitzicht op het behalen van de diploma’s.

In hoofdstuk 7, de algemene discussie, vatten wij de belangrijkste bevindingen samen en bediscussiëren wij methodologische overwegingen en de implicaties van dit proefschrift voor gezondheidsbevordering onder diabetespatiënten uit lage welstandsgruppen.

*Samen sterk met suiker* bevat veelbelovende interventie strategieën, zoals het oefenen van vaardigheden en het geven van feedback tijdens rollenspellen en het betrekken van familie en vrienden in het diabetes zelfmanagement door het maken van een gezamenlijk actieplan, die bij lijken te dragen aan een toename van sociale ondersteuning van familie, vrienden en groepsgenoten en een afname van sociale invloeden van familie en vrienden die zelfmanagement belemmeren. Verder concluderen wij voorzichtig dat de interventie bepaalde aspecten van diabetes zelfmanagement verbeterd lijkt te hebben zoals een beter begrip van de rationele achter diabetes zelfmanagement, het gebruik van meer complexe zelfmanagement strategieën en een toename in lichaamsbeweging. Wij konden deze bevindingen helaas niet bevestigen met een kwantitatieve analyse. Succesvolle wervingssstrategieën waren een uitnodiging van de huisarts en het bellen van mogelijke deelnemers na het verzenden van deze uitnodiging. Het behoud van deelnemers in de interventie werd gestimuleerd door de positieve gezellige sfeer en de interacties tussen groepsgenoten, door rekening te houden met praktische barrières en het aanpassen van de interventie aan de voorkeuren van de deelnemers. De lengte, aard en planning van de interventie vormden barrières voor het behoud van de deelnemers na drie maanden, terwijl het bellen van deelnemers en het vooruitzicht op het behalen van de diploma’s bijdroegen aan het overkomen van deze barrières.
Problemen met het werven en behouden van deelnemers, met het verzamelen van data uit de medische dossiers en met de vragenlijst die wij gebruikt hebben tijdens deze studie maakten dat we een aantal onderzoeksdoelen niet konden realiseren. Wij concluderen dat wij tijdens de interventie ontwikkeling meer aandacht hadden moeten besteden aan de haalbaarheid van de uitvoering van de interventie en de mate waarin deze acceptabel is voor huisartsen en patiënten. Door middel van een kleine pilotstudie zouden wij belangrijke barrières bij de werving en het behoud van deelnemers en barrières bij het verzamelen van data uit de medische dossiers hebben kunnen achterhalen. Daarnaast zouden wij tijdens een pilotstudie de vragenlijst beter hebben kunnen pretesten.

Tot slot levert dit proefschrift lessen op voor gezondheidsbevordering bij deze doelgroep. Ten eerste, hoewel de interventie werd gewaardeerd en werd ervaren als nuttig merkten wij dat de interventie niet volledig tegemoet kwam aan de behoeften van de deelnemers en niet helemaal paste bij hun dagelijkse levens. De deelnemers hadden vaak meerdere ziekten en te maken met financiële problemen, huwelijkspstanden, huiselijk geweld of de zorg voor familieleden die (langdurig) ziek waren. Deze problemen hebben een grote invloed op diabetes zelfmanagement. Hoewel de interventie als doel had om de deelnemers te leren omgaan met deze problemen ten behoeve van diabetes zelfmanagement, was dit niet altijd realistisch en haalbaar. Achteraf moeten wij concluderen dat de interventie verbeterd had kunnen worden door het investeren in het samen met de deelnemers plannen en ontwikkelen van de interventie. Het was beter geweest om niet van tevoren te bepalen dat de interventie zich moest richten op het sociale netwerk maar om de focus van de interventie te bepalen op basis van een open, neutrale, behoefteanalyse in samenwerking met de doelgroep en hun gemeenschap.

Ten tweede, wij hebben een aantal veelbelovende interventie strategieën gevonden die goed lijken te werken in deze doelgroep, zoals een inductieve onderwijsbenadering, het gebruik van niet traditionele onderwijsmethoden, het stimuleren van het groepsproces en een gezamenlijk actieplan. Er is meer onderzoek nodig naar deze strategieën voordat deze ten volle geïmplementeerd kunnen worden.

Ten derde, hoewel dit proefschrift een aantal veelbelovende interventie strategieën laat zien moeten we realistisch zijn met betrekking tot de resultaten die we kunnen verwachten in deze doelgroep. Op basis van de resultaten en de inzichten die dit onderzoek heeft opgeleverd met betrekking tot deze doelgroep, is het de vraag of het realistisch is te verwachten dat deze patiënten na het volgen van één interventie in staat zijn hun diabeteszelfmanagement zodanig te verbeteren dat dit leidt
Samenvatting

tot klinisch relevante veranderingen in hun metabole controle. Wij veronderstellen dat het verminderen van problemen die veroorzaakt worden door sociaaleconomische deprivatie, zodat diabetes zelfmanagement makkelijker wordt, wellicht een effectievere en meer duurzame oplossing is voor deze doelgroep. Deze patiënten hebben waarschijnlijk meer aan interventies met een focus op meerdere levensgebieden (zoals wonen, relaties, stress, werk, inkomen en educatie) naast gerichte diabeteszorg, dan aan interventies die zich richten op diabeteszorg alleen.

Tot slot concluderen wij dat deze interventie waarschijnlijk sociale steun, sociale invloeden en sommige aspecten van diabetesmanagement positief beïnvloed heeft en een aantal veelbelovende interventiestrategieën lijkt te bevatten die goed lijken te werken onder deze doelgroep. Toekomstige interventies die zich richten op diabetes zelfmanagement onder deze doelgroep zouden zorgvuldig moeten overwegen welke effecten zij verwachten te vinden onder deze doelgroep, en hun onderzoeksdesign hierop moeten aanpassen. Daarnaast is het waarschijnlijk dat deze doelgroep meer heeft aan een benadering die verder kijkt dan diabetes zelfmanagement door hen actief te betrekken bij de ontwikkeling van de interventie en het onderzoeksdesign en hen te vragen aan welke problemen zij zouden willen werken voordat diabetes zelfmanagement mogelijk is.
PhD Portfolio
Name PhD student: Charlotte Vissenberg  
PhD period: June 2008 – April 2013 (fulltime)  
May 2013 – January 2017 (parttime)  
Name PhD supervisor: prof. dr. K. Stronks  
Prof. dr. M.G.A.A.M. Nijpels  
PhD co-supervisor: dr. V. Nierkens  
dr. P.J.M. Uitewaal

1. PhD training

<table>
<thead>
<tr>
<th>General courses</th>
<th>Year</th>
<th>Workload (Hours/ECTS)</th>
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<tbody>
<tr>
<td>- The AMC World of Science (AMC Graduate School)</td>
<td>2009</td>
<td>0,70</td>
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<tr>
<td>- Clinical Data Management (AMC Graduate School)</td>
<td>2009</td>
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<td>- Practical Biostatistics (AMC Graduate School)</td>
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<td>- Regression Analyses (Erasmus University)</td>
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<td>- Project Management (AMC Graduate School)</td>
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<td>- Pretesting questionnaires to improve survey research (University Utrecht)</td>
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<td>- PHQ, website design (AMC Graduate School)</td>
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<tr>
<th>Specific courses</th>
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<tr>
<td>- Health Education &amp; Health Promotion: Theory and Practice (Maastricht University)</td>
<td>2008</td>
<td>1,40</td>
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<tr>
<td>- Intervention Mapping. Designing Theory-based and Evidence-based HIV/AIDS Prevention Programs (Maastricht University)</td>
<td>2008</td>
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<tr>
<td>- Klinimetrie: het ontwikkelen en evalueren van meetinstrumenten (VU medisch centrum)</td>
<td>2008</td>
<td>1,40</td>
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<tr>
<th>Seminars, workshops and master classes</th>
<th>Year</th>
<th>Workload (Hours/ECTS)</th>
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<tr>
<td>- Seminars at AMC dept. of Public Health (2 oral presentations)</td>
<td>2008-2013</td>
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<table>
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<th>(Inter)national conferences and presentations</th>
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<th>Workload (Hours/ECTS)</th>
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<tr>
<td>- Gecombineerde jaarvergadering 2008 van Nederlandse Diabetes Onderzoekers, Doorwerth, the Netherlands</td>
<td>2008</td>
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<tr>
<td>o Oral presentation: Diabetes self-management through supportgroups.</td>
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<td>- Nederlands Congres voor de Volksgezondheid (NCGZ), Rotterdam, the Netherlands</td>
<td>2009</td>
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<td>o Poster presentation: Het volhouden van therapietrouw met behulp van het sociale netwerk. Een interventie voor diabetikers uit lage welstandsgruppen.</td>
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<td>- Jubileumcongres 25 jaar werken aan interculturele GGZ. De gekleurde gekte, Mikado, The Hague, the Netherlands</td>
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<tr>
<td>o Poster presentation: Diabetes onder allochtone groepen. Praktijkvoorbeelden.</td>
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<td>- European health Psychology Society (EHP), Pisa, Italy</td>
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<tr>
<td>o Poster presentation: Powerful Together with Diabetes. A social network intervention for diabetics with a low socioeconomic status.</td>
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</table>
**PhD Portfolio**

- **2nd European Conference on Public Health (EUPHA), Lodz, Poland**
  - Poster presentation: Powerful Together with Diabetes. A social network intervention for diabetics with a low socioeconomic status.  
  - Year: 2009  
  - Workload: 1.00

- **World congress on Prevention of Diabetes and its Complications (WCPD), Dresden**
  - Year: 2010  
  - Workload: 0.50

- **3rd European Conference on Public Health (EUPHA), Amsterdam, the Netherlands**
  - Oral presentation: pretesting questionnaires among among people within low socioeconomic groups.  
  - Year: 2010  
  - Workload: 0.50

**Other**

- Meetings Network Qualitative Research AMC (monthly supervisions) and organisation of the symposium 'Mixed methods. A state of the art' (2009, Amsterdam, the Netherlands)  
  - Year: 2008  
  - Workload: 2.00

- Journal Club for PhD candidates, Department of Public Health (AMC-UvA)  
  - Years: 2009-2011  
  - Workload: 1.00

- Academic Collaboration for Public Health, 'Intervention Evaluation Club'  
  - Years: 2009-2013  
  - Workload: 1.00

**2. Teaching**

<table>
<thead>
<tr>
<th>Lecturing</th>
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<tr>
<td>Practice 'analyses of health problems and the implications for individual care', Medical faculty, AMC-UvA</td>
<td>2009 and 2010</td>
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<tr>
<td>Practice 'Culture and health in the course Cultural Diversity in Medical practice, Medical faculty, AMC-UvA</td>
<td>2009 and 2010</td>
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<tr>
<td>Course qualitative research, masters Evidence Based Practice, AMC</td>
<td>2009 and 2010</td>
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<table>
<thead>
<tr>
<th>Supervising</th>
<th>Year</th>
<th>Workload (Hours/ECTS)</th>
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<tr>
<td>Mieke Oudejans, intern of VU University: &quot;Dat vind ik gewoon een moeilijke vraag&quot;. Een kwalitatief onderzoek naar het achterhalen van obstakels bij het beantwoorden van vragen uit vragenlijsten voor type 2 diabeten met een lage sociaal-economische status.</td>
<td>2009</td>
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<tr>
<td>Fatmagül Kercpil, intern of VU University: Powerful Together with Diabetes. Pretesting materials of a social network intervention for diabetics with low socioeconomic status, including ethnic minorities.</td>
<td>2010</td>
<td>2.00</td>
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</table>

**Total** 30.80

ECTS= European Credit Transfer and Accumulation System; 1ECTS credit= 28 hours
PUBLICATIONS IN THIS THESIS


PEER REVIEWED PUBLICATIONS NOT INCLUDED IN THIS THESIS


OTHER


Dankwoord
Er zijn veel mensen geweest die een belangrijke bijdrage geleverd hebben aan dit proefschrift. Te beginnen met de mensen die betrokken waren bij de ontwikkeling en evaluatie van beide interventies.

Als eerste wil ik de mensen zonder wie dit onderzoek niet plaats had kunnen vinden bedanken: de deelnemers aan ‘Samen sterk met suiker’ en ‘Ken uw suiker’. Bedankt voor jullie enthousiaste deelname, het invullen van de vragenlijsten, het ondergaan van de lichamelijke onderzoeken en het geven van toestemming voor het inzien van jullie medische dossiers. De deelnemers die daarnaast ook bereid waren tot een diepte interview wil ik extra bedanken. Het zijn met name deze gesprekken, bij jullie thuis op de bank, geweest die ons veel inzicht hebben gegeven in jullie dagelijkse levens met diabetes.

Ook wil ik de deelnemende huisartspraktijken, de praktijkondersteuners en doktersassistenten bedanken voor hun inzet.

De groepsbegeleiders hebben ook een belangrijke bijdrage geleverd. Lida, Emmy, Miranda, Eveline, Wellston, Lahbib, Rahmi, Günay, Rhimou, Mary, Martijn, Yilmaz, Soumaya, Kübra en Saskia bedankt voor jullie enthousiasme, doorzettingsvermogen en flexibiliteit. Het opzetten en uitvoeren van een volledig nieuwe cursus was een hele kluif, maar dankzij jullie inzet is dit goed gelukt.

Diana Geraci wil ik bedanken voor haar inzet tijdens de ontwikkeling van beide interventies. Naast dat je een erg gezellige collega was, had je veel kennis over en ervaring met het opzetten van interventies. Bedankt voor de leuke interventie onderdelen (‘De brief van de week’ en ‘De diabetesquiz’ zijn echt jouw creaties) die je bedacht hebt en voor het trainen van de groepsbegeleiders.

Mirjam Kohinor wil ik bedanken voor het overnemen van mijn werkzaamheden tijdens mijn zwangerschapsverlof. Ik kon het project met een gerust hart aan jou overlaten. Bedankt ook voor de gezelligheid en de goede gesprekken door de jaren heen.

Leontien Fliek en Sanne Schepers, de trialmanagers van deze studie, bedankt dat jullie ervoor hebben gezorgd dat de dataverzameling goed verliep en dat de deelnemers de verschillende metingen op tijd kregen. Sanne, ook heel erg bedankt voor het vele werk dat je verricht hebt bij het opschonen van de databestanden.

Mieke en Fatmagül, de stagiaires op dit project, jullie hebben met jullie master thesis beide een belangrijke bijdrage geleverd aan dit project. Mieke, jij hebt een
aantal vragenlijsten uitgetest onder de doelgroep. Fatmagül, jij hebt een aantal interventieonderdelen uitgetest. Op basis van jullie onderzoeken hebben wij de vragenlijst en de interventie kunnen verbeteren, waarvoor bedankt!

Ik wil ook graag mijn begeleiders en collega’s bedanken.

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In the last 30 years, the number of people with type 2 diabetes has more than doubled globally. People living in socioeconomically deprived areas are disproportionately affected by this condition, and also have more diabetes-related complications.

Complying with and maintaining the complex health regimen needed for diabetes—known as diabetes self-management—is challenging for socioeconomically deprived patients. The social networks of patients play an important role in diabetes self-management. Relatives and friends can facilitate or hinder diabetes self-management, with social support and role models. The social networks of patients are also influenced by social pressures, social norms, and role models.

Powerful Together with Diabetes is a newly developed intervention with a focus on the social networks of patients living in socioeconomically deprived neighborhoods. It aimed to improve glycemic control by increasing social support and diminishing hindering social influences on diabetes self-management. This thesis describes the development and evaluation of the process and effects of this intervention.