Social support networks of diabetes patients
For reasons of consistency within this thesis, some terms have been standardised throughout the text. As a consequence the text may differ in this respect from the articles that have been published.

The studies presented in this thesis have been performed at the Scientific Center for Quality of Healthcare (IQ healthcare). This center is part of the Radboud Institute for Health Sciences (RIHS), one of the approved research institutes of the Radboud university medical center.

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Social support networks of diabetes patients

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Chapter 1

General introduction
BACKGROUND

Type 2 diabetes, prevalence and treatment

Diabetes is a chronic disease with a major impact on patients' quality of life and life expectancy. Of all cases of diabetes, type 2 diabetes comprises 90%\(^1\). The number of adults with type 2 diabetes in the European Union is increasing from about 53 million in 2013 to a predicted number of 64 million in 2030\(^2\). This increase in the prevalence of type 2 diabetes is strongly influenced by ageing populations and lifestyle related factors, such as diet and physical exercise. The impact of diabetes on patients' quality of life is high because the treatment of diabetes affects patients' lifestyle and involves blood sugar monitoring, and possible, diabetes medication and insulin therapy. Moreover, failing to control blood sugar levels can result in complications including a higher risk of cardiovascular disease, chronic kidney disease and failure, micro and macro vascular complications resulting in a diabetic food, neuropathy, and loss of vision\(^3\). Because of the healthcare costs involved, it also poses a major challenge for healthcare systems in economically developing and developed countries\(^4\).

Partly as a result of recent austerity measures, governments reduced healthcare expenditure and costs of care are increasingly being transferred onto patients\(^5\). As a consequence, patients with diabetes or other chronic disease have been made more responsible for the management of their health and disease\(^6\). This transfer of responsibility has greatest impact on patients with low incomes, as austerity measures affect them more than affluent groups. These developments have the risk to increase the health inequality, particularly because people with low socioeconomic status\(^7\) and in economically deprived areas\(^8\) are also at a higher risk of developing diabetes. Therefore, we can raise the question whether all diabetes patients seem to receive the support they need to manage their health and diseases.

In the treatment of diabetes, primary medical care has a central role in many countries. This starts with the diagnosis of diabetes and continues with the treatment and counselling, often with involvement of a nurse or practice assistant\(^9\). If we look at how self-management of diabetes patients is enhanced, we see that interventions often are based on strengthening individual competencies. This is reflected by the words that describe self-management support interventions: 'self-management', 'motivational interviewing', 'individual care plans', etc. For example, the clinical practice guideline on diabetes of the Dutch College of General Practitioners (NHG) advises that every patient should repeatedly receive patient education and lifestyle advises (no smoking, healthy diet, weight control, enough exercising) as a main component of the treatment\(^9\). Only if blood glucose levels remain high, drug therapy to reduce these levels such as metformin or insulin injections is advised. Despite the publication of practice guidelines, research has shown that the effects of patient education and lifestyle advice are mixed and the overall evidence for the effectiveness of such interventions is limited\(^10,11\). To be able to provide optimal care for patients with a chronic illness, social participation and supportive social support
networks are increasingly recognized as important for illness management. Although social support could potentially be effective, both from a financial and from a health perspective, less is known about how and under which circumstances this is the case.

**Potential of social networks**

A range of studies have shown that the social environment influences health behaviours and health outcomes\(^\text{12-16}\). This could comprise support provided through individual social networks with family and friends, but also support that is available in community organisations and local neighbourhoods. A range of theories have proposed mechanisms to explain the effect of social networks. Using a structural networks perspective, advanced statistical models have been developed to evaluate network dynamics and to predict changes in the structure of networks \(^\text{17,18}\). The underlying mechanisms from this perspective are based on processes of social selection and social influence. A different perspective is offered by functional theories, which focus on socio-psychological capacities and processes which are necessary to create and maintain social relationships\(^\text{19}\). These theories often use the notion of social capital to explain how social networks can contribute to health outcomes\(^\text{20}\).

Although the literature on social networks has contributed to understanding of the potential role of social networks in health and disease, many aspects remain unclear. For instance, it is not yet clear how the transfer of responsibilities to the patient and his/her social environment will affect health behaviours and health outcomes. And even if a social support network is beneficial, it is questionable whether all patients actually have such a network and know how to successfully make use of it. This will be necessary if social networks have to compensate for economic austerity policies. Therefore, more insight is needed regarding whether social networks are supportive for type 2 diabetes patients in general, and to deprived populations more specific. Also, it is not yet clear what specific network characteristics are supportive for health related outcomes and what their relative influence is. Also it remains unclear what kind of support is most beneficial for what type of group. With this in mind, we developed the objectives of the research presented in this thesis.

**MAIN OBJECTIVE**

The overall aim of this thesis is to improve the understanding in the characteristics of social support networks and to gain insight in the relationship between social networks and self-management within diabetes type 2 patients, with a particular focus on people with socioeconomic deprivation. Specific objectives were:

- To identify emerging policies and practices regarding diabetes care in The Netherlands.
- To explore the structural characteristics of social support networks of type 2 diabetes patients and the association with the volume of social support received.
• To examine the impact of different types of support and social networks on self-management capabilities, health, and health-related behaviours in patients with type 2 diabetes.
• To explore which theory-based mechanisms are relevant to type 2 diabetes patients in generating a social support network.

THE EU-WISE PROJECT
The data used in this thesis is collected as part of the EU-WISE project (www.eu-wise.com). EU-WISE is a project under the 7th Framework Programme with a collaboration of six European countries: Bulgaria, Greece, the Netherlands, Norway, Spain and the United Kingdom. The overall aim of this project was to offer a better understanding of the mechanisms involved in the management of type 2 diabetes within different contexts, with emphasis on people with socioeconomic deprivation. The project used a whole system approach, in terms of system level (professional, organisational, and patient) as well as a methodological approach, using quantitative and qualitative methodologies and systematic literature reviews. Finally, an intervention based on the former studies was developed and assessed. Most of this thesis will make use of the quantitatively collected patient data, however chapter 2 uses data collected on all levels (different stakeholders) and chapter 8 uses qualitatively collected patient data.

STRUCTURE OF THIS THESIS

Chapter 1 provides an introduction to this thesis and presents the main objectives. In chapter 2 we present a description of emerging trends in diabetes care practice and policy in The Netherlands. In this way we describe the societal context at the time of the research. Chapter 3 presents the protocol of our study. It provides a theoretical background for this thesis and a description of the data collection and measures that have been used to answer the objectives of this study. Chapter 4 elaborates on the data collection for this specific type of research. It shows how data collection in the setting of our research can be optimised. Chapter 5 illustrates how supportive networks look like and how these networks differ between socioeconomic status groups. This provides more information on the potential support available in social networks. Both chapter 6 and 7 show how network characteristics are related to health outcomes. Chapter 6 focuses on patient-reported health status, physical exercise, diet and smoking, chapter 7 focuses on self-management capabilities. Chapter 8 provides a qualitative elucidation of the network related mechanisms that we found in chapters 5 through 7. This thesis ends with a general discussion of the topics presented throughout chapter 2 to 8 and will come back to the main objective presented in chapter 1.
REFERENCES


Chapter 2

Emerging trends in diabetes care practice and policy in The Netherlands: a key informants study

Michel Wensing
Jan Koetsenruijter
Anne Rogers
Maria Carmen Portillo
Jan van Lieshout
ABSTRACT

Background: Effective self-management is viewed as the cornerstone of diabetes care. Many interventions and policies are available to support self-management, but challenges remain regarding reaching specific subgroups and effectively changing lifestyles. Here, our aim was to identify emerging policies and practices regarding diabetes care in The Netherlands.

Methods: Study with a purposeful sample of key informants, covering a range of stakeholders. They were individually interviewed, using a flexible and semi-structured approach. A thematic analysis was done, guided by an international framework, which resulted in 28 themes.

Results: After a decade of investing in diabetes care in The Netherlands, stakeholders seem to have shifted their focus towards a view that effective self-management is expected in most people. The expectation is that individuals' personal networks, community organisations and emerging information technologies will facilitate this. If support of self-management is required, this has to be provided by local coalitions of health and social care organisations, with involvement of municipalities. Poor reach in specific subgroups of the population, such as economically deprived people, is recognised but has not led to targeted policies.

Conclusions: The role of healthcare providers in supporting patients' self-management in diabetes care seems to be changing in The Netherlands.
BACKGROUND
The prevalence of diabetes is rising worldwide, with highest figures in low- and middle-income countries\(^1\). Life style interventions can effectively reduce the incidence of diabetes type 2 in high-risk patients\(^2\). In many countries, a range of interventions and policies are being applied to support self-management in people with diabetes. In The Netherlands, diabetes care is largely provided in primary care, involving physicians, nurses, dieticians, physiotherapists and other professionals. On average, about four different disciplines of healthcare providers were involved in the care of a patient with diabetes\(^3\). In addition, patients' relatives and community organisations are viewed as having a role to play in the self-management of people with diabetes.

Since 2005, a number of policy measures have focused on optimising conditions for diabetes care: a national multidisciplinary guideline has been published to guide optimal clinical management, patient education tools are widely available, targeted reimbursement for diabetes care has been created, and improving diabetes care is a prominent target of quality improvement in primary care. These strategies have been enhanced by a nationally convened coalition of stakeholders, which created and implemented a national action plan to improve diabetes care in the years 2008 to 2013\(^4\). Despite these efforts, and similar programs in other parts of the world, there remains room for further improvement in diabetes care\(^5\).

As the nationwide effort to improve diabetes care came to an end in 2013, we wondered what new practices and policies were being considered and emerging in diabetes care in The Netherlands. The macro-economic conditions since the year 2008 have been characterised by increasing uncertainty about household incomes, rising unemployment rates, and policies to lower spending on public services, including healthcare. People with chronic conditions are affected by the consequences of this development in a variety of ways, particularly if they live in economically deprived circumstances\(^6\). The available social systems of support, including personal social networks and community organisations, may counterbalance these potentially negative developments and provide support to efforts of self-management\(^7\).

Stakeholder analysis has been identified in health policy as a method for assessing the viability of future policy options and identifying appropriate strategies and contexts for implementation\(^8\). Here, our aim was to identify stakeholders' views on emerging trends in diabetes care practices and policies in The Netherlands, with a particular interest in self-management of people with diabetes.
METHODS
A study involving interviews with key informants was undertaken, following the guidance provided by a written study protocol in the context of the EU-WISE project (available on request from the authors). In The Netherlands, new policies and practices typically first emerge in the health policy arena or in local projects, rather than in the government or related bodies. Therefore we used qualitative research methods to identify what had not yet been documented in national policy papers or formalised programs. The RATS guideline for qualitative research was consulted when writing the paper. This guideline describes a number of features for high-quality publications of qualitative research, which can also be used to design good qualitative studies. All data were handled confidently and reported anonymously. Ethical approval was not required as we did not involve patients in the study.

The study was based on a purposeful sample of 15 key informants, who represented various stakeholders in diabetes care in The Netherlands. Using professional networks, we identified people who could provide relevant information, given their skills or position in society. We planned to include individuals from different stakeholder organisations, covering a range of relevant disciplinary backgrounds and professional roles. Each of these individuals was expected to have knowledge, which was not held by others, thus we were not necessarily expecting saturation in the interviews. The number of 15 informants was pragmatically determined, assuming that a diversity of views could be documented in this way. The participants were interviewed between December 2012 and April 2013 by one of two interviewers, both non-clinician health researchers. The order of the interviews with key informants was pragmatically determined, based on their availability for interviews.

The interviews were designed to identify emerging practices and policies in diabetes care, with a special focus on self-management. The interviews used a few open questions to trigger responses, followed by questions to clarify or illuminate specific items. The interviews started with a broad question (“what are in you view most relevant developments in diabetes care?”), followed by mentioning a few trends relevant for self-management to elicit responses (these items changed over time as a result of interim-analyses), and ending with an open question focused on self-management in people in deprived conditions (“Have macro-economic trends influenced the role of deprivation and thinking about self-management?”). The interviews were undertaken face-to-face or by telephone with the informants at their work setting, and took 30 to 45 minutes each. Directly after each interview, the interviewer made a written summary (paraphrasing closely the responses and including crucial citations ad verbatim) and a short reflection on the content from the perspective of the interviewers. Four interviews were fully recorded and transcribed verbatim to check the adequacy and comprehensiveness of our summaries, which proved to be good. Some respondents provided suggestions for policy documents, from which key points were included in the summaries of the interview.
The qualitative analysis was conducted concurrently with the data collection, led by the first author and involving the second author (both had done the interviews)\textsuperscript{11}. An initial analysis after five interviews identified a number of emergent themes. These were elaborated in a further round of interviews, which also included prompts to elicit new themes. This process was repeated after 10 interviews. After all interviews had been completed, we used a modified framework approach to analyze the data\textsuperscript{12}. After familiarisation with the data, an initial thematic framework was developed inductively from the interview data in The Netherlands. This was followed by a comparison with the frameworks based on similar key informant interviews in five other countries (Bulgaria, Greece, Norway, Spain, United Kingdom), which were done as part of the EU-WISE project. In a two-day international workshop in the Spring of 2013, we developed an integrated thematic framework. The categories of this integrated framework were then applied deductively to the interview data. In an iterative process, further country-specific themes were then identified inductively for each of the categories in this framework. Finally, the interview data were organised according to the identified themes and used to generate interpretations that are provided below.

**RESULTS**

Table 1 lists the characteristics of the 15 key informants. We managed to include all stakeholders as planned, but could not reach representatives of relevant industry (e.g. food industry, software developers who were implicated as being relevant respondents as data collection progressed).

<table>
<thead>
<tr>
<th>Function</th>
<th>Association</th>
<th>Public sector</th>
<th>Private sector</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Policy-makers</td>
<td>Academics</td>
</tr>
<tr>
<td>1</td>
<td>Scientific research coordinator</td>
<td>Diabetes charity</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Project coordinator</td>
<td>Health insurer</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Policy advisor curative healthcare</td>
<td>Ministry of Health</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Professor in applied health research</td>
<td>University Medical Centre</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Chairman Primary care cooperation / GP / Scientific researcher</td>
<td>Primary care cooperation / GP-practice / University Medical Centre</td>
<td>X</td>
</tr>
<tr>
<td>6</td>
<td>Coordinator diabetes care / GP-expert in diabetes care</td>
<td>Primary care group</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Dietician</td>
<td>Dutch Dietician Organisation / National Programme for Diabetes</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Health consultant / Science practitioner</td>
<td>Local authority / University Medical Centre</td>
<td>X</td>
</tr>
<tr>
<td>9</td>
<td>Staff member ethnic minorities</td>
<td>Senior wellbeing organisation</td>
<td></td>
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</tbody>
</table>
While we mainly included high-level stakeholders, many of the informants were also active at local level (for instance, as healthcare provider). Table 2 presents an overview of the 28 themes that were identified in the stakeholder interviews in The Netherlands. Quotes are presented to illustrate key points.

Table 2. Overview of themes

<table>
<thead>
<tr>
<th>Themes in the international framework</th>
<th>Themes that are specific for The Netherlands</th>
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<tr>
<td>Macro level policies</td>
<td>National government delegates tasks to municipalities</td>
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<td></td>
<td>Municipalities delegate tasks to local organisations</td>
</tr>
<tr>
<td></td>
<td>Municipalities delegate tasks to the individual and his/her network</td>
</tr>
<tr>
<td></td>
<td>Integration of healthcare, social care and prevention</td>
</tr>
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<td></td>
<td>Diabetes is regarded best practice example for chronic illness care</td>
</tr>
<tr>
<td>Recent changes in practices and local policies</td>
<td>Introduction of practice nurses in primary care</td>
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<td></td>
<td>New reimbursement system for diabetes care</td>
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<td></td>
<td>Policies for supporting local communities</td>
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<td></td>
<td>Emergence of online patient education and counselling tools</td>
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<tr>
<td></td>
<td>Prevention of diabetes remains important</td>
</tr>
<tr>
<td>Rationale for changes in policy and practices</td>
<td>Promotion of ‘chronic care model’ to decision makers</td>
</tr>
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<td></td>
<td>Self-management of disease as way to improve quality of life</td>
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<td></td>
<td>Containment of rising costs of health and social care</td>
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<td></td>
<td>Health information technology as emerging market</td>
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<tr>
<td>Evidence on the impact of changes in practice</td>
<td>Changes in biomedical indicators of diabetes care quality</td>
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<tr>
<td></td>
<td>Poor reach of in specific subgroups</td>
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<td>Factors influencing change of practice</td>
<td>Changes in primary care populations</td>
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<td></td>
<td>Instruments for tailoring to individuals</td>
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<td></td>
<td>Together self-management</td>
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<td>Healthcare providers’ skills</td>
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<td>Contextual factors</td>
<td>Financial incentives for primary care</td>
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<td></td>
<td>Price of medication</td>
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<td></td>
<td>Wide adoption of modern information technology in primary care</td>
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<td>Deprivation not on national agenda</td>
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<tr>
<td>Role of stakeholders</td>
<td>Effective lobby by collaboration of stakeholder in diabetes care</td>
</tr>
<tr>
<td></td>
<td>Health insurers</td>
</tr>
<tr>
<td></td>
<td>Primary care</td>
</tr>
<tr>
<td></td>
<td>Municipalities</td>
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</table>
National policies
The first category in the framework concerned the national policies regarding health and social care, which are relevant for people with diabetes. In The Netherlands, these reflect a shift of responsibility for tasks at different levels:

National government delegation of tasks to municipalities
In recent years, an important principle of the national government has been that many activities are delegated to community level, involving municipalities, because this is expected to help tailoring to local and individual needs. The idea is that self-management support for chronic conditions achieves better integration with other types of support for vulnerable people, such as solving financial debts and housing problems. The focus of the government's health policy is to organise healthcare close to patients domestic arrangements, in their municipalities.

Municipalities delegates tasks to local organisations
Not only the national government is delegating tasks to municipalities, the latter are delegating tasks downwards to local organisations. The role of local authorities is to coordinate and facilitate, but they do not have the financial resources to do much of the practical work. The role of the local authority appears to have shifted from top-down interventions towards more of "a think along" strategy without direct interventions. The shift is towards creating links between all relevant organisations and facilitating local activities. This means that local wellbeing organisations, sport clubs and other organisations are important partners offering possibilities for a more active lifestyle.

"As local authority we have to withdraw ourselves, (as we are) facing the recent cuts. But we try to place responsibilities as much as possible to those organisations. We encourage and do tell them what we want, and which direction we would like to go."
[Informant 15]

Municipalities delegate tasks to the individual and his/her network
The idea of recent policies of municipalities is as follows. Self management is construed as people being more responsible themselves for their own wellbeing, help by professionals is no longer guaranteed. Instead, the focus of support is seen as emanating from within someone's own social network. If people need support, then local authorities will check if they can arrange this within their own local connections. Family, neighbours or volunteers can even help to organise this. If this is not possible, the local authorities can still step in. The new policy relies on the idea of self responsibility and less on professional care. This means that a patients' social network will be used to deliver a structural part of the necessary care and professionals will operate more as coaches to organise and facilitate care. More attention will be given to the support of informal
carers so they can deliver more and better care. Only if patients cannot organise the necessary care within their own network will professional help be provided.

**Integration of healthcare, social care and prevention**

The increased role of local organisations and patient networks alongside health professionals creates the need for more cooperation to deliver the necessary care for patients with a chronic condition. To undertake this task, they will have to work together with primary care physicians and other primary care professionals. This collaboration between local organisations and primary care is going to be one of the most important changes in the future care for chronic diseases. An important development is the increased cooperation between GPs, local authorities and community services. Local authorities become more important in the distribution of resources and use these to promote specific activities. Primary care providers know which interventions patients need and can refer them to relevant community services. Therefore it is necessary that GPs become more aware of the possibilities for activities within a local community. Coordination of services is high on the agenda and expected to contribute to reducing the costs of public services. A development is the introduction of the trajectory ‘paradigm’ which intends to reduce fragmentation in health and social care. Each patient is supposed to get his or her own case manager to coordinate the care.

"That's what we would like to achieve, to create a vital neighbourhood where the care is efficient. Where professionals thus know which care is offered and can cooperate" [Informant 15].

**Diabetes is regarded as a best practice example for generic chronic illness care**

Diabetes is regarded an "ideal case" for general policies for chronic illness care. There are many diabetes patients, thus there is much attention in the policy world for diabetes, and a set of procedures that can be implemented to improve outcomes for diabetes patients. A previous Minister of Health has invested in care standards and related activities, partly inspired by a study trip to Kaiser Permanente in the US. At the Ministry, the perception is that diabetes is an important topic for primary care physicians, and that they appreciate the information available to illustrate quality of diabetes care, and The Netherlands performs well as compared with other countries.

**Recent changes in practices and local policies**

Several changes in practice and local policies were mentioned by the key informants, which were perceived to have impact on diabetes care. Note that many of these changes were coordinated at national level as presented below.
Introduction of practice nurses in primary care
An important shift was the transformation of diabetes care from a specialist service (provided in hospitals) to primary care, involving nurses to deliver most of the care. This shift occurred about a decade ago in The Netherlands.

New reimbursement system for diabetes care
Additional reimbursement has been created for diabetes care in recent years. In the current situation, the organisation of budgets for diabetes care are stimulating incentives to detect diabetes and to treat it. The knowledge generated by local improvement projects was used to develop criteria for contracting healthcare providers. In addition, the optional additional insurance package (which everyone can choose individually) includes a number of self-management items: a course to stop smoking, membership of a patient organisation, participation in physical exercise programs. Some items, such as stop smoking programs, may be included in the basic insurance in the future. It is also increasingly an issue for collective insurance packages (arranged through employers or otherwise, e.g. the elderly association is also a collective). These tend to place value on preventive services more generally.

Emergence of online patient education and counseling tools
Another important development in self management is related to e-health. Different organisations are working on developing and implementing internet based portals where patients can access health care providers and manage their own illness related information. For instance, the platform ‘www.thuisarts.nl’ is an initiative of the Dutch College of General Practitioners. It offers general information as well as the option to create a personal space. Another example is ‘mijnzorgpagina.nl’ which is an initiative from the Dutch Diabetes Association. This is a website especially for patients with diabetes or other chronic diseases and gives patients the possibility to create a personal profile. The site contains a number of programs that could help a patient, such as putting together a healthy meal, monitoring blood glucose or other parameters, and checking their body weight. Because patients can create their own profile, they can personalise this website and have directly access to relevant information, support and contacts with other patients. In relation to self-management the sites raise questions and monitoring around whether the patient become more active in their own treatment, and independence in testing and regulating blood sugar.

Prevention of diabetes remains a key focus
A controlled study on screening for pre-diabetes did not provide evidence for impact, but early detection of diabetes is still viewed as important. For one local authority diabetes care is not identified as a priority, but promotion of healthy life styles is considered very important, especially to prevent overweight and obesity developing in young people.
Rationale for and influences on changes in policy and practices
The key informants provided a number of reasons, when asked for the rationale for recent changes in policy and practices. Some of these changes are described in more detail:

Promotion of 'chronic care model' to decision makers
A major development in policies relevant for self-management was the publication of care standards for a range of chronic diseases in the first decade of the years 2000. These have been developed for diabetes, COPD, and vascular risk management. These care standards aim to support healthcare providers and patients in achieving optimal healthcare for their chronic condition. All care standards recommend that each patient has an explicit (written) individual treatment plan, which is relevant for self-management. This is an agreement between patient and professional about treatment goals and planned activities, including lifestyle changes. The idea of the Chronic Care Model proposed by Wagner has led the development in this field. A more structured approach is expected to lead to a better care and reduced costs.

"The chronic care model has led in The Netherlands to the development of care standards for diseases such as diabetes. Care standards are documents developed and supported by different stakeholders and are important for policies. Part of those standards is the improvement of self management, individual treatment plans and the implementation of those plans." [Informant 4]

Self-management of illness as a means of improving quality of life
The government ideology is one in which that there is a great willingness in society to help each other and one which wants to promote the philosophy that people can function independently. It wants to discourage the idea that people have a right to specific services, simply because these exist and there is regulation that indicates that they are entitled to receive those. A policy for people with chronic conditions and elderly people in general focus on participation (in a broad sense) and the ability to self manage. Participation means to them that people participate in the society and have contact with other people in the neighbourhood and local services. Self management is considered to be the ability to participate without (much) intervention from professionals.
Underlying these policies is a neo-liberal political view that people are responsible for their lives. This implies less focus on the government and on collectively organised prevention of disease. Self-management fits in the broader theme of the quality of life of patients, which is a recognised domain of psychological interventions and research for many health funders. Although self-management applies to patients, it was noted by our respondents that the word is only used by professionals and virtually never by patients. Besides this view on self-management, the most important part of self-management is not dealing with illness but health promotion and prevention of diseases.
**Containment of rising costs of health and social care**

Although cost containment may be linked to self-management in policy rhetoric and plans, the logic underlying this was challenged by several informants. For instance, one did not consider a self-management approach as a way to save money and whilst motivational dialogues are expected to result in better health outcomes, although experiences suggest that this is not a less intense way of treatment and not cheaper than traditional healthcare.

**Health information technology as emerging market**

The involvement of private parties (IT companies, pharmaceutical industry, etc.) is welcomed by the national government. These organisations tend to ask little support from the government, except for regulation (e.g. obligatory certification of providers). The Ministry of Health sees private parties as an important source of innovation in healthcare and society more broadly, also in the domain of self-management. This view is consistent with broader policies regarding scientific research of the Dutch government, which seeks to link science closely to economic development.

**Evidence on the impact of changes in practice**

We asked the informants about evidence on the impact of changes in practice as a result of emerging trends in practice and policy. Two issues emerged from data: Changes in biomedical indicators of diabetes care quality One informant reported that there is evidence for increased health outcomes, but not for reduction of costs. However, most key informants did not have a clear view on the evidence for impact of changes in practice.

**Poor reach to specific population subgroups**

Several informants expressed concern about the poor reach in specific subgroups in the population, notably in people in socioeconomic deprived conditions. However, the impact of deprivation on ability to self-manage was perceived to be mixed. Self-management programs tend to emphasize one's own responsibility and it is likely that people from lower socio-economic groups find it harder to join groups on their own. Patients need to master the Dutch language, being capable to plan actions and perform them and need the right motivation to do so. The patients that ultimately join a self-management intervention are just a small and very selective group from all patients. On the other hand, deprived areas tend to receive more attention and more professional healthcare workers operate in those areas. Some groups, such as specific ethnic minorities, are well organised, so that they can be reached more easily. However, this is not the case for all relevant subgroups. One of the interventions is to introduce lifestyle coaches who go to peoples own place and help them to join sport or exercise groups. This is a specific intervention for lower SES groups.
Factors influencing change of practice
When asked for factors influencing desired change in practice ("barriers and facilitators"), the key informants mentioned a number of items. Note that health system-related factors will be discussed in the next section.

Changes in primary care populations
A relevant trend in the patient population (besides ageing) are that criteria for diagnosing diseases are stretched (so that more people are diagnosed). Another is that many patients are transferred from hospital to primary care (e.g. after treatment for cancer) so that many vulnerable patients are now under treatment in primary care. As a consequence, more vulnerable patients are dependent on primary care.

Instruments for tailoring to individuals
Specific instruments can be used to tailor self-management support to the individual patient. Not everybody can directly start self-management. In one chronic care group, a structured screening tool has been developed and is currently implemented and evaluated in primary care. It distinguishes three categories of patients: individuals who only need some information and can then help themselves, individuals who need to develop some skills first, and individuals who continue to need instruction and are not ready for self-management.

Together self-management
An informant at a large health insurer noticed that self-management is only effective "when somebody is standing next to the patient". This can be a relative, case manager, or coordinating professional. This has emphasized for the health insurer's policies the direction of 'together self-management'. A researcher notices that as long as the interventions lasts patients do their exercises, but fail to continue those after the interventions finishes.

Health providers' skills
Healthcare professionals can be examined regarding their skills to provide self-management. Evaluations suggest that there is room for improvement. Nurses in primary care need to be qualified to deliver a self management program.

"Are all primary care nurses ready to develop self-management interventions? I think this will take some time, especially to develop the necessary skills" [Informant 14].

Contextual influencing factors
A number of contextual factors were mentioned by respondents, which were perceived to influence change in practice regarding diabetes care:
Financial incentives for primary care
Initiatives to improve care for deprived groups are organised by GPs, but these mostly depend on the initiative of individual GPs and do not belong to common healthcare. According to this respondent GPs do not have financial incentives to organise care and wellbeing beyond their boundaries and they cannot be forced to do so.

Price of medication
A substantial number of pharmacies did not sign contracts with health insurers. The implication is that patients have to pay cash in the pharmacy, which is problematic and causes aggression in some cases – particularly in deprived areas. Pharmacies with contracts have different price levels (as a consequence of the health insurer’s policy to discriminate between pharmacies). This is difficult to explain to patients, again particularly in deprived areas. Pharmacists feel that the government falls short in explaining the system to the public.

Emerging information technology
A growing number of tools aim to facilitate self-management. Some allow professionals to stay in contact with patients, check and monitor medications without face to face contact. Some information technology firms promote the use of portals to share information with patients. However, the introduction of e-health is not yet implemented widely. This is partly due to the fact that not all elderly are able to work with computers/tablets, although an increasing group of patients can use those devices.

Deprivation is absent from the national agenda
Reaching lower economic status groups is not an explicit target of the Ministry of Health and there are no specific policies targeted at this item. The tendency at the Ministry is to argue "these problems can be solved with a little bit of creativity". Financial deprivation was not an explicit item in the government policies, but one informant thinks that it is emerging. It was defined in terms of specifying different target groups and enhancing the social support system at a local level. This was explicitly presented as an interpretation of signals by this informant rather than a clear fact. There has been some research on the link between SES and health care outcomes in the last decades, but recently there is not much interest on this topic. A focus on self-management might increase the existing gap between groups. Although a self-management program will do no harm, groups with a higher SES will benefit more than lower SES groups.

"It is likely that groups that needed least care are best capable to organise themselves and live healthy are the best in performing self management as well. And other, more vulnerable groups, are probably less capable in self management and thus increasing the difference between groups". [informant 4]
Role of key stakeholders
The key informants gave also specific information on the role of key stakeholders in diabetes care, which is summarised below.

Effective lobbying by collaboration of stakeholder in diabetes care
Diabetes charities collaborate with healthcare providers and patients in the national diabetes federation (NDF). This collaborative has coordinated a four-year action program, which ended in 2013. This was mainly focused on implementation of the "care standards": a set of organisational guidelines that intend to facilitate the implementation of clinical guidelines as well as patient empowerment. An informant of the health insurer perceived an increased awareness that a collaborative approach (involving several stakeholders) is needed to make progress. A group of stakeholders met to discuss the possibility of creating a national action plan for self-management. National action plans exist for other topics, e.g. prevention, involve all relevant stakeholders, with the Ministry of Health not necessarily in the lead.

Health insurers
An important stakeholder are the health insurers. They work together with local authorities and health professionals to deliver tailored (health) care where it is needed most. Another way health insurers are involved is in their effort to shift care for chronic diseases from hospitals to GPs and homecare. Health insurers do not want to decide what is optimal diabetes care but take the published care standard as starting point for their policies. Health care insurers are not involved in the policy making but do have some influence because they can chose to financially support projects that they think are worth full. For example, the support and education for informal carers was strongly supported by a health care insurer.

Primary care providers
The agenda on self-management for chronic diseases is mainly influenced by professional health care organisations. The primary care physicians' organisation is considered the most influential partner in the policy for self-management.

Municipalities
As indicated in the section on national policies, a shift is occurring from national funding of long-term health and social care towards funding by local authorities or health insurers.

DISCUSSION
This study in key informants provided a view on emerging practices and policies in diabetes care in The Netherlands in the year 2013, with a particular focus on self-management of people with diabetes. After a decade of investing in diabetes care in The Netherlands, and five years after the start of the macro-economic crisis, policy makers seem to agree that effective self-management
is desirable in people with diabetes. Effective self-management is viewed as the cornerstone of diabetes care. The expectation is that individuals' personal social networks, community organisations, and emerging information technologies will facilitate this. If professional support of self-management is required, this has to be provided by local coalitions of health and social care organisations, with involvement of municipalities. Poor reach in specific subgroups of the population, including economically deprived people, is recognised but has not led to targeted policies.

Like all countries, The Netherlands is a special case, which has its unique characteristics. Nevertheless, we believe that many themes are also relevant in other countries. For instance, the macro-economic problems and the prevailing neo-liberal ideology have led to stronger emphasis on self-management of chronic diseases all over the world. Also, a lot of people informally supporting other people exist in many countries, although the configurations and underlying views vary and the precise role and contribution made by a network of personal contacts has not been elaborated. Reaching deprived people with chronic diseases in programs to enhance their health and quality of life is a challenge in most countries. Further studies in the EU-WISE project aim to explore the similarities and differences of these practices and policies across a range of European countries.

This study had strengths and limitations. The flexible approach to sampling and interviews helped to identify items that are not yet well documented. The range of key informants added to the richness of the data. The current study lacks views from relevant industries (e.g. food industry, supermarkets, software developers), although we attempted to include key informants from these stakeholders. We could have included other types of key informants, such as practice nurses. Examination of the available transcribed interviews provided confidence that our interview summaries were a valid starting point for the analysis. Also, the internationally integrated thematic framework provided support to the validity. Nevertheless, we cannot fully rule out the possibility that the non-transcribed interviews contain data that has been missed. We did not attempt to identify deviant cases in the analysis, but it is obvious that several practices and policies are potentially conflicting. For instance, the heavy emphasis on information technology solutions conflicts with the wish to reach deprived people with low literacy skills.

The implementation of self-management support in chronic care management is far from completed in most European countries. The translation of the emerging views and practices into nationwide policies is often a slow and haphazard process. The Dutch healthcare system is characterised by distributed decision making, so that none of the stakeholders can enforce its views on healthcare. In addition, programs for improving healthcare are complex, implying that its components influence each other and may lead to unpredictable outcomes. Therefore it remains to be seen whether, and how quickly, the identified trends will be widely adopted in practice and policy. This will be influenced by contextual factors, such as the persistence of the macro-economic problems and the dominance of the neo-liberal ideology. The findings of this study are best regarded as a set of options, from which decision makers may chose.
Conclusions

Effective self-management is viewed as the cornerstone of diabetes care. The expectation is that individuals' social networks, community organisations, and emerging information technologies will facilitate this. If professional support of self-management is required, this has to be provided by local coalitions of health and social care organisations, with involvement of municipalities.
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Chapter 3

Social support systems as determinants of self-management and quality of life of people with diabetes across Europe: study protocol for an observational study

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ABSTRACT

Background: Long-term conditions pose major challenges for healthcare systems. Optimising self-management of people with long-term conditions is an important strategy to improve quality of life, health outcomes, patient experiences in healthcare, and the sustainability of healthcare systems. Much research on self-management focuses on individual competencies, while the social systems of support that facilitate self-management are underexplored. The presented study aims to explore the role of social systems of support for self-management and quality of life, focusing on the social networks of people with diabetes and community organisations that serve them.

Methods: The protocol concerns a cross-sectional study in 18 geographic areas in six European countries, involving a total of 1,800 individuals with diabetes and 900 representatives of community organisations. In each country, we include a deprived rural area, a deprived urban area, and an affluent urban area. Individuals are recruited through healthcare practices in the targeted areas. A patient questionnaire comprises measures for quality of life, self-management behaviours, social network and social support, as well as individual characteristics. A community organisations’ survey maps out interconnections between community and voluntary organisations that support patients with chronic illness and documents the scope of work of the different types of organisations. We first explore the structure of social networks of individuals and of community organisations. Then linkages between these social networks, self-management and quality of life will be examined, taking deprivation and other factors into account.

Discussion: This study will provide insight into determinants of self-management and quality of life in individuals with diabetes, focusing on the role of social networks and community organisations.
INTRODUCTION

Background

Long-term conditions, such as diabetes and cardiovascular disease, pose major challenges for healthcare systems in economically developing and developed countries\(^1\). Diabetes type 2 is an increasingly prevalent condition with major impact on mortality, quality of life, and healthcare costs\(^2\). The prevalence of diabetes is rising as a consequence of ageing populations and unhealthy lifestyles. In the European Union, about 53 million adults aged 20–79 years had diabetes in 2013 with a predicted number of 64 million in 2030\(^2\). People with low socioeconomic status\(^3\) and in economically deprived areas\(^4\) are at a higher risk of developing diabetes. Healthy lifestyles contribute to the prevention and improvement of this condition, while drug therapy is crucial for the prevention of long-term complications\(^5\). Therefore, optimising self-management of people with diabetes (and many other long-term conditions) is an important strategy to improve health related quality of life and other outcomes, as well as improving the sustainability of healthcare systems. However, the effects of patient education and counseling on health-related life styles and adherence to treatment are mixed and the overall evidence for the effectiveness of such interventions is equivocal\(^6,7\). So the challenge is to optimise the reach and effectiveness of self-management support for people with long term conditions, particularly in vulnerable groups, such as people living in socially and economically deprived conditions\(^8\). Social participation and supportive social networks are increasingly recognised as important for illness management and may offer new perspectives for enhancing quality of life in people with chronic illness\(^9\).

Self-management is a complex concept, which has been defined in different ways. We use the following definition: "the care taken by individuals towards their own health and well-being: it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition; and to prevent further illness or accidents"\(^10\). Self-management has been estimated as being beneficial for 70-80% of people with chronic conditions, and forms part of a wider agenda about public health, health promotion and patient involvement in different health systems across Europe\(^10\). Some effort has been made to identify groups that benefit most from self-management interventions. A study in the UK suggests that younger people and people with lower self-efficacy and health-related quality of life improve most by this type of interventions\(^11\) and a Danish study shows that a low educational level hinders participation in self-management programs\(^12\). Literature also indicates that self-management interventions might be less attractive to males\(^13\).

The current economic crisis in Europe has forced many governments to cut budgets for health expenditure. Self-management, which focuses on the patient taking the lead in the management of his or her condition, might offer a possibility to reduce use of healthcare services and thus costs. Likewise, social support for self-management might contribute to lowering of healthcare costs. Although both self-management and social support to improve self-management seem to
be driven by societal need and also by ideology, scientific knowledge of the impact of social support and underlying influencing factors remains limited\textsuperscript{14}. Some indication is given by a study in the UK suggesting that community and network-centred approaches may be particularly relevant for engaging people in socially and economically deprived areas\textsuperscript{15}. Another study in the United Kingdom\textsuperscript{16} explored social support systems of people with diabetes.

The study protocol presented here, as part of the EU-WISE project (EU-WISE is a research project funded by the EU’s Seventh Framework Programme), builds on this research and will examine the role of social support and networks in self-management for people with diabetes type 2 across Europe. The overall aim of the EU-WISE project is to provide better understanding of mechanisms involved in the management of diabetes, with a specific focus on socially disadvantaged people, on enhancing better self-management in peoples' everyday lives and local communities, as well as on developing an understanding as to how this will work within different contexts. The EU-WISE project comprises a range of studies, using a mix of research methods. Literature studies on structure and governance of health and welfare systems, personal networks and community group networks will be done in the EU-WISE project as well as a qualitative and quantitative study. Finally, we will work on the development and assessment of an intervention based on the former studies. This study protocol concerns a quantitative survey study that is part of the EU-WISE project.

**Aims and objectives**

The study has two overall aims: (1) to describe and explore the role of social networks in providing support to people with diabetes, (2) to describe and explore the role of community organisations (including healthcare providers in the community) which intend to support people with diabetes. The following overall objectives have been specified:

1. To describe the key aspects of the individual's social network, social support and self-management in individuals with diabetes in six European countries, with a particular focus on people who are economically deprived or marginalised.
2. To describe the community organisations that support self-management in people with diabetes, and to map out the connections between these organisations.
3. To explore the associations between aspects of individuals' social networks, affiliation with community organisations, self-management, healthrelated lifestyles, with a focus on individual’s quality of life and a special interest in the role of socioeconomic deprivation (as specified in Figure 1).

**Theoretical background**

The role of social networks and community organisations for individual quality of life is mitigated by their role in health-related life styles, which are often described as self-management. Self-management of diabetes is demanding in many ways: it involves cognitive, practical and socio-
emotional tasks. Drawing on personal capabilities, social networks, and the support available through the healthcare system, some people manage their diabetes well. For others, the capacity to self-manage is limited by medical problems, psychological factors, economic constraints, cultural influences, and lack of social capital\textsuperscript{17}. While self-management has often been defined as an individually-centred concept, there is growing recognition of the need to consider contextual factors in the self-management of long-term conditions\textsuperscript{15}. This notion is consistent with epidemiological research evidence. For instance, a systematic review found that the likelihood of survival was higher in people with stronger social relationships\textsuperscript{18}. It is also illustrated by empirical studies, which show that the range of health-related behaviours are not randomly spread in a population, but linked to social network structures\textsuperscript{19-21}. This has led to the notion of hypothesized "contagion processes" operating in social networks, which seem to apply to a range of items, including the spread of happiness, health-related behaviours, diseases and risk factors (e.g. smoking, obesity, and depression)\textsuperscript{9,22}. The underlying mechanisms of contagion patterns are probably heterogeneous, depending on the item of interest. For behaviours, psychological mechanisms such as imitation of successful behaviours, role modelling and social comparison may explain contagion.

Different theoretical perspectives provide clues for identifying the relevant social system-related or contextual determinants of self-management in people with diabetes. Social-constructivist theory emphasizes that individuals develop ideas and behaviours in interactions with others, thus building realities that influence the frame of reference of individuals. This may suggest that self-management is influenced by social networks, regarded as "systems of support" or "communities of practice". These include personal communities, community organisations, health professionals, and non-health professionals\textsuperscript{23}. A realist review of studies suggests that social networks have a range of functions, including shaping of knowledge, discourses and narratives; shaping of stigma and deviance; negotiation of responsibilities and coordination; relationships with health services; and substitution of health professionals by lay networks\textsuperscript{15}. Community organisations that provide support for people with long term conditions may be more responsive to social and environmental influences on condition management than traditional health services\textsuperscript{24}. Network ties may operate through connections from patients to local organisations as part of a pathway of care as well as raise awareness of the group’s activities with other organisations through inter-organisation networks.

The concept of social capital can help to explain how social context influences self-management and quality of life in people with long term conditions. Social capital has been defined as an individual characteristic related to somebody’s networks, such as access to people or entities with relevant resources (e.g. information, practical help, access to medical care)\textsuperscript{25}. Many survey studies use this individual-centred definition to explore relations between social capital and health outcomes in populations, without stating clear conclusions about the dynamics involved,
due to lack of consistency in definition, measurement and plausible theories to explain the obtained correlations\textsuperscript{26,27}. A further limitation is the predominance of individual ("ego") networks rather than whole networks, that also include connections between friends or family members ("alters").

Later definitions of social capital define it as a quality of social relationships or society at large, focusing on social trust that facilitates cooperation for mutual benefit\textsuperscript{25}. In empirical research, this notion translates into analyses of the impact of the social capital of geographically defined neighbourhoods on their members' health status\textsuperscript{28}. The notion that social capital may be conceptualised as a feature of relations rather than individuals has some resonances with the sociological theory of the emergence and persistence of cooperation, although this focuses on specific network structures rather than using social systems metaphorically. This theory offers explanations for the development of cooperation in social systems, which imply a (risk of) loss for the decision-maker in the short-term compared to alternative behavioural options\textsuperscript{29}. Altruistic behaviours, such as providing social support, can be seen as a special type of cooperation. The theory suggests, among other things, that cooperation is more likely in situations with (anticipation of) high likelihood of repeated contact and exchange (direct or indirect reciprocity), high density of connections (reducing "free rider" behaviours), as well as a physical location or position in a social network that is close to potential partners for collaboration.

A social network approach can thus make a positive contribution to applying the knowledge from social capital literature to the study of self-management and quality of life. In this research project, we will focus on a number of system-related determinants of self-management in people with diabetes. The empirical measures focus on the connections between individuals and between community organisations, which are relevant for receiving information on disease and management, practical help with daily tasks, or emotional support. Self-management behaviours, health-related life styles (smoking, physical exercise), quality of life and patient reported health status are outcomes of interest. In particular, the relevance of the following factors will be explored:

- Determinants with direct impact in the individual's social network ("social capital factors"), such as ego-network size, number of connections with perceived high helpfulness, number of individuals in the wider network who have health-related knowledge, distance and frequency of contact with network members, diversity of types of relationships.
- Determinants indicating the impact of network structures ("contagion factors"), such as ego-network density, number of closed triads, homogeneity of the network in terms of age and gender.
- Determinants linked to individuals' affiliations in the wider social system ("system factors"), such as the number of linkages of the individual to community organisations, density of connections between community organisations, deprivation of the neighbourhood.
To explore the effects of these determinants, we will study them across a wide range of countries, areas and individuals reflecting different levels of deprivation, urbanisation and austerity policies.

In the study, we will also consider and (where possible) control for the influence of individual characteristics, such as age, gender, diabetes severity, co-morbidity and educational level.

Figure 1 provides a schematic global overview of the main domains (blocks) of factors in the study and their relationships (arrows), which will be explored in this research project.

**Figure 1. Conceptual framework for the study**

Legend: Blocks refer to clusters of variables and arrows refer to expected causal effects.

**METHODS**

**Study design**

An observational study in two related parts is planned: a cross-sectional observational study in individuals with diabetes (recruited through healthcare practices) and a survey of representatives of community organisations. The research will be conducted in 18 purposefully chosen geographic areas in 6 countries, which reflect a variety of healthcare systems: Bulgaria, Greece, the Netherlands, Norway, Spain and the UK. Thus, the study has a nested sampling design: individuals are nested in healthcare practices, both are nested in geographic areas, which are nested in countries. We plan to include community organisations, which are nested in the same geographic areas. The study is undertaken in six country-specific research teams, which have received approval from the countries’ relevant ethical committees to take part in the research. A full list of ethical committees approving this study can be found in Additional file 1.
**Setting**

In each of the participating countries, research will be undertaken in three purposefully selected geographic areas: a deprived urban area (e.g. an area in a city); a relatively affluent urban area; and a deprived (relative to country) rural area. Urban is defined as located in a city with more than 100,000 inhabitants. Rural is defined as located in towns or villages with less than 30,000 inhabitants. We will use a high percentage of households with low household income as an indication for the socio-economic deprivation of a region. The affluent area has been included to explore the impact of geographical area on the outcomes. More specifically, we expect to find differences regarding the type and number of community organisations and levels of social trust between deprived and affluent areas. The rural area was included because people in those areas were expected to face different challenges in self-management behaviours.

In each country, these areas were chosen close to each other when feasible (the urban areas ideally in the same city) in order to get a relatively homogenous sample and thus some control for contextual factors (confounders related to area characteristics). There was no intention to get a representative set of areas for a larger region or country. In this way, we planned a study in 18 areas spread over 6 countries (ideally, clusters of 3 geographically closely located areas in each of 6 countries). From a statistical perspective, countries and geographical areas are considered ‘fixed’ (no statistical generalisation beyond chosen areas and countries).

**Sampling of adults with diabetes**

We plan to recruit a sample of 300 individuals in each country (100 in each area) with diabetes type 2. Inclusion criteria are: medical diagnosis of diabetes (not a patient reported diagnosis); type 2 diabetes only (no type 1, but comorbidities such as cardiovascular disease are allowed); age of 18 years or over. Exclusion criteria are: no established diagnosis of diabetes, but (e.g.) obesity or high risk for developing diabetes; mix of type 2 and type 1 (not pure type 2 diabetes); pregnancy; pregnancy-related diabetes; recent/current major surgery or medical procedures; severe cognitive or psychiatric handicap; terminal illness/receiving palliative care; absence of translators (e.g. family members) for patients with insufficient language skills.

Eligible patients will be recruited from healthcare practices (primary care practices in most countries) in the chosen geographical areas. Recruitment of individuals from primary care contexts is preferred because it has the advantage of a confirmed diagnosis of diabetes by a physician and provides the possibility of a face to face contact with the patient. This face to face contact, rather than just mailing a written or online questionnaire, is planned to enhance recruitment, especially for people from a deprived background\(^30\).

Eligible patients will be given an invitation letter and a written questionnaire. The letter describes the study and the request to the patient to complete a written questionnaire and to be
interviewed. Patients who give informed consent will be followed up by the researchers if they fail to complete interviews. The total number of individuals invited to participate will be recorded in order to calculate a participation rate.

**Sampling of community organisations**

We plan to recruit up to 150 representatives of community and volunteering organisations per country (the number of organisations is probably lower than the number of representatives). The sample will consist of up to 150 respondents who will be purposefully selected to include community organisations that operate on the national, regional, and local level. The organisations will be selected, as much as possible, in the same geographical areas where the individuals with diabetes will be recruited. As some organisations do not operate in specific regions (e.g. webbased communities), we do not expect a total overlap between the areas where patients and organisations are recruited.

The recruited organisations will consist of community and volunteering organisations offering illness-relevant support to people with diabetes. Four main types of organisations are targeted: diabetes-related organisations; health- and healthy lifestyle-related organisations; well-being-related organisations; people’s and patients’ rights organisations. Diabetes related organisations are groups and organisations that have a direct focus on health improvement specifically on diabetes e.g. diabetes foundations and diabetes education organisations, associations and forums. Health- and healthy lifestyle-related organisations are groups and organisations that can improve health outcomes but do not explicitly focus on people with diabetes. These can include exercise-related organisations, diet groups and organisations for elderly people, which may have impact on self-management behaviours (e.g. walking groups). The third group refers to well-being-related organisations such as community centres where people meet and socialise (e.g. discussion circles). The fourth category of organisations consists of people’s and patients’ rights organisations that protect the position of patients. These could include for example advocacy groups for diabetes patients and elderly rights organisations. We will also include the healthcare providers, who provide access to individuals with diabetes for sampling, in the sample of community organisations.

To identify relevant community organisations we will adopt a bottom-up approach. The research teams in each country will start identifying a set of key organisations that are the most relevant within each type of organisations. Next, a combination of different approaches can be adopted with respect to the attributes of a specific country and area. These approaches are:

- Use the list of organisations suggested by other project partners and try to identify similar groups and organisations in each country.
- Use the information provided by one or more key persons knowledgeable about the areas where data will be collected e.g. a GP, a community centre, local council, etc.
• Include organisations that are mentioned in the patient’s interviews.
• Use the first group of organisation interviews to identify other organisations with the help of the snowballing procedure.

In each organisation, a representative may be an individual who is closely involved with the management of day to day operations, and/or the strategic development of the group/organisation. Larger organisations with independent groups in different areas, e.g. diabetes groups affiliated with Diabetes UK are seen as local branches. We will treat these as separate organisations and representatives of each of these groups can be interviewed separately. If the research team wants to interview two or more different representatives of the same local organisation this will be allowed. The purpose of this would be to get more reliable data on the key links of the organisation, which will increase the validity of the information from the surveys (less likely to be useful for smaller organisations).

**Statistical accuracy**

The planned study will include diabetes patients (n=1,800), primary care practices (n=36 to n=96), support organisations (n=300 to 900), geographical areas (n=18) and countries (n=6). To assess the statistical accuracy of the associations between aspects of individuals’ social networks and support, affiliation with community organisations, self-management and health status a tentative power analysis was done. Based on $\alpha = 0.05$, power = 0.80 and the inclusion of eight independent variables in the analysis the sample size will allow the detection of a medium effect size ($\chi^2 = 0.15$)\textsuperscript{31}. Because of the clustering of patients within areas (reflecting both country differences as well as primary care practices differences and regional differences), we took the design effect into account. Between-practice variation for aspects of patients' health status or behaviours tend to be low compared to measures of healthcare delivery\textsuperscript{32}. A study on diabetes patients in primary care practices showed on most outcome measures an intraclass correlation coefficient (ICC) $< 0.05$\textsuperscript{33}. Relevant outcome measures such as the SDSCA and SF-12 showed an ICC of 0.022 and 0.028. We therefore assume an ICC of 0.03. The design effect is calculated as $DE = 1 + (m-1)\rho$, with 100 patients per cluster, resulting in design effect of 3.97 and an effective sample size of $1,800/3.97 = 450$ patients. This effective sample size is sufficiently large to detect a medium effect size.

**Patient questionnaire measures**

The study uses a pre-structured patient questionnaire, which utilises both established and purposefully constructed measures in order to explore a range of domains. The questionnaire has two parts. The first part includes a written questionnaire with demographic variables quality of life items, selfcare, received care and participation in local organisations. The second part is a face-to-face or telephone interview, which will provide information on the social networks and support of the respondents. When available, we use measures that have been translated into
relevant languages, validated in several health systems, provide reference data (for comparison), and shown to be feasible in people with low education (thus, short and simple). The source-versions of the questionnaires are available in English. If no validated translation into country-specific languages is available, a structured procedure for translation, involving forward and backward translations is applied. Table 1 provides an overview of the measures included in the patient questionnaire.

Table 1. Overview of measures in patient questionnaire (English versions)

<table>
<thead>
<tr>
<th>Measure</th>
<th>Concept</th>
<th>Number of items</th>
<th>Link</th>
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</thead>
<tbody>
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<td>Individual health status</td>
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<tr>
<td>European Social Survey</td>
<td>Well being</td>
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<td>Selfcare behaviour and life style</td>
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Written questionnaire
As outcome measures we will measure both individual health status as well as physical lifestyle. To measure functional health status we will use the SF-12 with 4-week recall. This a patient reported health status measure developed to measure the disease burden, both physically as mentally. Besides health status we also measure health-related well-being, using two items from the European Social Survey which measures happiness and life satisfaction (www.europeansocialsurvey.org).

To assess physical life style of respondents, the Rapid Assessment of Physical Activity (RAPA) is used to measure physical life style of respondents. This questionnaire was developed to measure the level of physical activity of older patients. The Summary of Diabetes Self-Care Activities (SDSCA) assesses selfcare behaviour and life style because selfcare for diabetes patients is closely related to life style. The SDSCA measures behaviours such as diet, smoking, physical exercise, blood sugar testing and foot care. Medication adherence as a selfcare behaviour is assessed using the Morisky Medication Adherence Scale (MMAS-4). This questionnaire measures both medication adherence as well as barriers for medication adherence. Selfcare cognitions are measured by two domains from the HEIQ V3.0: the self monitoring and insight domain and the skill and technique acquisition domain. The former assesses the ability of patients to measure their condition and their insight in performing selfcare. The latter captures the patient's knowledge and ability to perform the actions to relieve the disease symptoms.

As intermediate variables we retrieve data on the medical and social care received in the past six months with the use of the Diabetes Health Care Utilization questionnaire. This questionnaire is developed to measure health care utilisation by a self reported list. Furthermore we collect demographic data, including patients' age, sex, family situation, education, employment status, sick leave, ethnicity, housing, global household income and comorbidities. In order to map out affiliation networks we also measure involvement in regional or national support organisations.

Interview
In interviews with patients data on their social network and social support will be collected. First, the name generator method is used to generate a list of relevant individuals and using probes for family members; friends, neighbours, colleagues; and professional care providers. Next, for each listed individual we will collect a number of characteristics, including gender, age, type of connection and the received support according to pre-defined domains: information, treatment, day to day tasks, and emotional support. From the named individuals ("alters") the perceived connections between each individual will be listed as this is crucial for mapping out the complete ego-network. Finally, the position generator is used to identify access to people with specified healthcare professions. All questions have been tested before data collection started using cognitive testing techniques.
Community organisation questionnaire measure
A telephone or face-to-face survey will be conducted with individuals who represent a support organisation. The questionnaire is purposefully developed and covers the following domains: descriptive information on the organisation and its activities; reach in target group in terms of users of information, participants in activities; collaboration with other support organisations in the local area, including primary care healthcare practices; contact/collaboration with other organisations in domains that are relevant to self-management behaviours.

Measures concerning primary care practices and geographic areas
At a higher organisational level we will collect data on the characteristics of healthcare practices, geographic areas, support organisations, and contexts from which patients are recruited. Concerning each practice we will collect information about the practice size in terms of number of patients and staffing e.g. number of physicians, nurses, and assistants. In primary care practices, will collect some items about the practice organisation. Concerning each geographic area we will collect some descriptive information such as the urban/rural nature, deprivation, number of inhabitants and age structure.

Data analysis
Data collected in different countries will be checked for integrity and then included into a comprehensive database, which will be finalised prior to data analysis. In the first phase of the analysis, the characteristics of individuals and organisations will be described, including the social networks. Scale scores and network measures will be constructed in this phase. This provides answers to research questions 1 and 2. The second phase of the analysis addresses research question 3 and comprises an exploration of linkages between system-related factors (in social networks and community organisations) on the one hand, and self-management, health-related lifestyles and quality of life on the other hand, taking deprivation and other factors into account (Figure 1).

To explore the relevance of system-related factors for patients’ self-management and other outcomes (research question 3) we will develop and test a number of hypotheses. First we will explore determinants based on the idea of social capital. We expect that more social capital will result in better self-management and a higher quality of life. Relevant determinants for social capital are: egonetwork size, number of connections with perceived helpfulness, number of individuals in the wider network who have health-related knowledge. Second, we will explore the role of contagion in social network structures. We expect individuals to adopt behaviour from other network members more often if a network has a higher density, more closed triads and a higher homogeneity in terms of age and gender. The third perspective takes the wider social system into account. We expect that more individual embeddedness into community organisations will result in better self-management and a higher quality of life. Moreover, we
expect that a higher density of connections between community organisations and a lower deprivation of the neighbourhood will lead to better self-management and a higher quality of life in individuals.

In all analyses, we will consider a range of other factors including age, gender, diabetes severity, co-morbidity and educational background. In particular, we will examine whether the main effects (e.g. of social support and community organisation on self-management behaviours) are moderated by deprivation levels.

Network characteristics will be calculated using specific social network analysis software. For other analyses we will use multilevel regression models, taking clustering on the level of country, area and healthcare provider into account. To reduce the possibility of chance capitalisation, we will use $p < 0.05$ in hypothesis-driven analyses to indicate significance, but in explorative analyses we will use $p < 0.01$. Testing differences between countries is not planned as the sampling method does not allow inference to countries, but we will take country differences into account when interpreting the results.

**DISCUSSION**

The current economic crisis in Europe has forced many governments to cut budgets for health. Self management is seen as one possible way reduce costs, forcing the patient to take the lead in his/her health and shifting social support towards family and community organisations. This implies that social support is expected to be more often delivered by family members and community organisations and stimulating them to take on new areas such as support for self-management. Some research on the role of social support and community organisations has been done, suggesting that community and network-centred approaches may be particularly relevant for engaging people in socially and economically deprived conditions\textsuperscript{15}. We will explore the effect of social capital factors, contagion factors and system factors on self-management and quality of life. Thus the study provides a systems perspective on how individuals with chronic illness use self-management to improve their health and quality of life. To explore the effects of these determinants, we will study them across a wide range of countries, areas and individuals, reflecting different levels of deprivation, urbanisation and severity of austerity policies.

The social network approach of this study is likely to make a contribution to applying the knowledge from social capital literature to the study of self-management support. Moreover, the wide range of settings can provide us a better understanding how self-management and social support will work within different contexts. Finally, we will provide insight into the potentially moderating influence of social networks and social support on the negative impacts of deprivation on self-management and health-related behaviours.
REFERENCES


Chapter 4

Higher monetary incentives led to a lowered response rate in ambulatory patients: a randomised trial

Jan Koetsenruijter
Jan van Lieshout
Michel Wensing

ABSTRACT

Objectives: Monetary incentives can increase response rate in patient surveys, but calibration of the optimal incentive level is required. Our aim was to assess the effect of different monetary incentives on response rates to calibrate the optimal monetary incentive for ambulatory patients. Study Design and Setting: A patient-randomised trial was performed in which targeted individuals received different gift vouchers (€5.00, €7.50, €10.00, and €12.50) on completion of a survey and interview. Eligible patients (diagnosed type 2 diabetes, over 18 years) were recruited from primary care practices. Results: The response rate for the €12.50 incentive was lower compared with both the €7.50 and the €10.00 incentive (odds ratio (OR) = 0.60 and OR = 0.58). A nonlinear model yield a better fit than a linear model. Within the observed range of incentive levels, an overall decrease in response rate was found. Conclusion: High monetary incentives are not only inefficient but also less effective.
INTRODUCTION
Low response rates in a sample of individuals who have been invited for a study induce a risk of selection bias and increase research costs. A range of interventions to enhance response rates has been tested, with variable and overall small-to-moderate effects. Monetary incentives have been applied to enhance survey response rates and showed an overall positive effect with an odds ratio (OR) of 1.87\(^1\,^2\). Offering money may be perceived to compensate for the individual’s time and to express appreciation for the willingness to participate. Increasing the amount of the incentive has been found to result in a higher response rate (OR = 1.26\(^3\)\(^4\), although a meta-analysis suggested that this effect flattens out at higher incentive levels, resulting in marginal increases for highest incentives. Therefore, calibration of the optimal monetary incentive to enhance response rates for a specific study population is still an important task. Given the decreasing relative value of money with increasing individual income, the effect of monetary incentives may be highest in low-income populations.

In this study, we aimed to assess the effect of different monetary incentive levels on response rates in a written survey and telephone interview in ambulatory diabetes patients. As we targeted individuals in both economically deprived as affluent areas, we were also interested the explore differences across geographic deprivation levels regarding the impact of monetary incentives. Overall, we expected that higher incentives lead to a higher response rate but with diminishing returns as the amount of the incentive increases. Moreover, we expect this curve to flat out at higher incentive levels in deprived areas as compared with affluent areas.

METHODS
A patient-randomised trial with four arms was performed in the Netherlands, in which targeted individuals received different gift vouchers on completion of the survey. The trial was integrated in an international observational multicenter study in primary care, which is described elsewhere. The ethical committee Arnhem-Nijmegen waived approval for the response trial2013/098, which was registered with Current Controlled Trials ISRCTN95158258. Data were collected in the year 2013.

Study population and setting
Eligible patients (diagnoses of type 2 diabetes, age 18 years or over) were recruited from primary care practices in three regions in the Netherlands: an urban deprived region, an urban affluent region, and a rural deprived region.

At the primary care practice, patients were given an invitation letter, which described the study and a written questionnaire. We planned to recruit a sample of 100 individuals in each region.
Interventions to enhance response rates
Patients were randomised to study arms within each general practitioner (GP) practice. At the GP practice, the patient was handed over an anonymous and closed envelope with the questionnaire and in which a specific monetary incentive was offered. Respondents were offered one of four incentive levels: €5.00, €7.50, €10.00, and €12.50. Neither the researcher nor the contact person at the GP practice knew the amount of money that was offered. Patients were asked to complete a questionnaire, which took about 15 minutes, and to participate in a telephone interview, which took an additional 15 minutes. The incentive was delivered on completion of both the questionnaire and telephone interview.

Outcome and statistical power
The primary outcome of this study was completion of the written survey and the telephone interview. The study was powered to detect an medium effect size (Cohen's d 0.3; OR = 1.72) between the incentive groups.

Statistical analyses
The response rate in each study arm was calculated, overall and within the three different regions (subgroup analysis). To test the effect of an increase in level of incentive, we performed a logistic regression analysis with the €5.00 as reference. We determined the fit of regression models with linear and nonlinear terms. We tested (1) whether the incentive level had a linear effect vs. no effect and (2) whether a nonlinear model fitted better than a linear model with the observed response rates. To estimate a nonlinear model, we added the square of the incentive in euro's to the model. A loglikelihood ratio test was used to compare the fit of these models.

Linear model: \[ Y = B_0 + B_1 \times \text{incentive} + e \]

Nonlinear model: \[ Y = B_0 + B_1 \times \text{incentive} + B_2 \times \text{incentive}^2 + e \]

RESULTS
In total, 520 individuals were invited and handed over a questionnaire. Out of these 520 invitations, 232 completed the questionnaire and participated in the telephone interview. This resulted in an overall response rate of 44.6% (not shown). The response rate was 40.2% for the lowest incentive level (€5.00), 50.0% for €7.50, 50.9% for €10.00, and 37.6% for the highest incentive of €12.50 (Fig. 1).

The response rates showed variation between the regions: 37.0% in the urban deprived region, 45.3% in the urban affluent, and 53.7% in the rural deprived region (not shown). The effect of the incentive seemed to vary between regions. In the urban deprived region, the response rate was
nearly the same for different incentive levels, whereas the urban affluent and rural deprived showed the highest response rate at an amount of €7.50 and €10.00 euro and the lowest at €5.00 and €12.50.

Logistic regression analysis showed that the response rate for the €12.50 incentive was significantly lower than for the €7.50 as the €10.00 incentives (OR = 0.60 and OR = 0.58, respectively). Other effects were not significant. The linear model did not have a better fit than the base model with no effect. The nonlinear model of incentive levels on response rates had a significantly better fit (X²(1) = 13.9 P < 0.001). The negative parameter for B₂ (-0.037) indicated that an increase in incentive resulted in a diminishing response rate. In the observed range of values for incentives, we found a decline in response rate that implicates that the ceiling of the effect of incentives on response rate was reached (Fig. 1).

**Figure 1. Response rate per incentive and region**

![Graph showing response rate per incentive and region](image)

**DISCUSSION**

This study showed a nonlinear relationship between the size of the monetary incentive and the response rate in a survey of ambulatory patients. Offering more money had positive impact on response rates but only up to a point. To our knowledge, this is the first trial in ambulatory patients that showed decreased response rates for higher monetary incentives. We found no evidence for the hypothesis that monetary incentives have higher impact in deprived areas.

The study has a robust design, but generalisability to other populations and settings is an issue for future studies. For example, patients with type 2 diabetes are relatively old and younger populations might have different considerations to participate. Because of the chosen method
(handing over questionnaires at a GP practice), we did not have name and addresses of the non-respondents and therefore we were not able to correct for potential non-response bias.

Although the positive but diminishing marginal effect of increased monetary incentives is consistent with previous studies\(^7\), we can only speculate about the reasons for the decline of response rates for highest incentives. Dillman\(^8\), who described questionnaire response in terms of a social exchange, suggested that when the amount of an incentive (rewards) approaches that of the effort to complete a questionnaire (costs), the response may decline. Part of this social exchange is the idea of reciprocity, the balance in "gifts" between two subjects\(^9\). If the incentive is perceived as too high for the effort, people feel that the "norm of reciprocity" is imbalanced and may withdraw themselves from participation. However, this effect has not been found in recent studies\(^5\). Alternatively, the finding may suggest that offering money to enhance response rates is mostly perceived as an appreciation of effort and less as realistic compensation of time involved in study participation. Also, a high incentive may be perceived to indicate high burden for responders or suggest other negative experiences. An important implication of our finding is that calibration of the size of monetary incentives to enhance response rate is required because high incentives are not only inefficient but also less effective.
Higher monetary incentives led to a lowered response rate

REFERENCES


Chapter 5

Social support in type 2 diabetes patients: a structural layout

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ABSTRACT
We studied the structural characteristics of social support networks of people with type 2 diabetes and the variation between high and low socioeconomic status groups. In a cross-sectional study we recruited type 2 diabetes patients in six European countries using questionnaires and subsequent interviews. We used multilevel regression modelling to assess the effect of structural network characteristics on the volume of social support.
In total 1,692 respondents completed the questionnaire and interview. Social support networks were small (3.2 members) and dense (density = 0.89). Differences between SES groups regarding network characteristics were small. Larger support networks were linked to less support per network member (beta = -0.07).
The presence of close family and spouse are beneficial to maintain a highly supportive network. However, also non-family links to healthcare providers and community organisations were linked to extra support. Larger networks may not necessarily increase support but can reduce the burden for individual network members.
BACKGROUND

Support for people from within their personal social networks is increasingly seen as relevant to maintaining the well-being and engagement of people living with long-term conditions such as type 2 diabetes. The role of social networks is likely to be relevant for people with long-term conditions because their personal network is the setting where individuals have to manage their condition on an everyday basis over long periods of time. Various studies have shown that social support and social networks are associated with the adoption and maintenance of health-related behaviours\(^\text{1-4}\) and health status\(^\text{5,6}\). Whilst studies have shown that networks can be positively associated with health related outcomes\(^\text{6,7}\), less is known about the properties of network structures which are actually involved in the provision of support and how illness supportive network structures might vary.

In examining whether an individual has a strong social support network, many studies have been predicated on the intuitive notion of social support which includes a focus on the role of the spouse, other close family members, and the size of a network\(^\text{8}\). In many support networks, women seemingly provide more illness management support than men and married people experience more support than people without a spouse\(^\text{9,10}\). However, structural characteristics e.g. density and heterogeneity tend to be overlooked in favour of exploring the determinants of the potential support that social network members can generate. In the broader field of social network analysis the use of advanced methods for quantitative analysis offers up the opportunity for eliciting new insights into the structure of networks. Based on social selection and social influence mechanisms, parameters have been developed to describe and express influences on network change\(^\text{11}\). These parameters describe network structures in terms of density, heterogeneity, and multiplexity. For example, a high density network with many connections could have a positive effect on the amount of support provided because actions within a network might be better coordinated\(^\text{12}\) and generate more pathways for a better flow of information through the network\(^\text{13}\). Heterogeneous networks are characterised by the inclusion of members with different characteristics and permits each network member to provide additional information and new types of support. Multiplexity is the idea that one network member can undertake multiple types of support which can improve coordination between tasks and efficiency of support because they are completed by the same person\(^\text{14}\). However, such support networks may become vulnerable if most of the support relies on one or a few people and multiplex networks have the tendency to be more homophilic and therefore provide less variation in type of resources\(^\text{15,16}\). Exploring these and other structural network features hold the potential to generate a better understanding of how network structures influence processes that generate or influence social support. Currently, empirical research applied to patients with long-term conditions is required to explore the role of these mechanisms.

Many studies to date fail to address the efforts that are necessary to create and maintain a network. These efforts require exploration and application to a range of tasks such as the navigation and negotiation to turn existing relationships into those that provide support for a
long term condition. This involves judgments about which relationships require reshaping, strengthening, abandonment, and developing new ones\textsuperscript{17}. It has been shown that difficulties encountered in this process can result in negative effects from social interactions\textsuperscript{7,18,19}. It could be hypothesised that in order to receive maximum support, optimally people should be embedded in a large network in which every network member is very supportive. However, it might also be the case that in order to be more efficient, a smaller network in which every member is supportive is preferable to a larger network which requires more effort to maintain. This suggests that there may be an optimal network size, which balances efficiency and viability. In addition to understanding the structures of social support networks, how these networks differ in different contextual and cultural settings is also of relevance. One potential in the supply of social support is the generation of compensatory input by members of social networks to compensate the impact of austerity. In order to explore whether this function is manifest, it is necessary to demonstrate that low socioeconomic status (SES) populations receive at least the same amount of support and that this support is beneficial for patient outcomes. Research has identified differences between high and low SES populations in the extent to which network characteristics are supportive, although both groups appear to benefit from a supportive network\textsuperscript{20}. However, it is not clear how and if these supportive networks in and of themselves structurally differ between the low and high SES groups. Previous research has shown that higher status is associated with higher levels of social support\textsuperscript{9}, but not the characteristics and mechanisms which result in lower status groups receiving less support. A proposed explanation is that lower SES individuals have more homogenous networks (i.e. same low-income level) which are likely to cope with similar stressful situations and therefore be less able to provide emotional support\textsuperscript{21,22}. Another explanation could be that limited resources make it more difficult to reciprocate which makes it harder to maintain ties and accept support\textsuperscript{23}. Also, individuals with lower SES tend to rely less on support from friends and more on support from family ties, although research is not conclusive on this trend\textsuperscript{21}.

In this paper we aimed to answer the following questions:

\begin{itemize}
  \item What are the structural characteristics of social support networks of people with type 2 diabetes?
  \item Which differences exist regarding the structural characteristics of social support networks between high and low SES groups?
  \item What structural network characteristics are associated with the volume and type of social support received?
\end{itemize}

**DATA AND METHODS**

*Study design, setting and participants*

An international cross-sectional study in patients with type 2 diabetes was conducted. Data were collected as part of the EU-WISE project; an integrated research project under the 7th
Framework Programme of the European Commission\(^24\). The study was conducted in 18 purposefully chosen geographical areas in six countries, reflecting a variety of health and welfare systems: Bulgaria, Greece, the Netherlands, Norway, Spain, and the United Kingdom. Within each participating country we selected three areas: one deprived urban area; one relatively affluent urban area; and one deprived rural area (relative to the country). We defined urban as located in a city with more than 100,000 inhabitants, whereas rural as located in towns or villages with fewer than 30,000 inhabitants. This stratified sampling of areas (rather than a completely random sample in each country) allowed us to study both individual and area characteristics. Because the areas were chosen purposefully, they are not necessarily representative for the countries involved. In each area, 100 patients with a diagnosis of type 2 diabetes were recruited, resulting in about 300 patients in each country. This number allowed us to detect a medium effect size (\(f^2 = 0.15\)) based on \(\alpha = 0.05\), intraclass correlation coefficient (ICC) = 0.03, power = 0.80 and the inclusion of eight independent variables in the analysis\(^24,25\).

Patients attending primary or ambulatory healthcare practices in the defined geographic areas were recruited. This method of recruiting has the advantage of a confirmed diagnosis of diabetes by a physician and provides the possibility of a face-to-face contact with the patient. Inclusion criteria were: medical diagnosis of type 2 diabetes and aged 18 years or over. Exclusion criteria were: pregnancy; pregnancy-related diabetes; recent/current major surgery or medical procedures; severe cognitive or psychiatric handicap; terminal illness/receiving palliative care; absence of translators (e.g. family members) for patients with insufficient language skills. Eligible patients were given an invitation letter with information, a consent form, and a written questionnaire via their healthcare practice. Participating patients were then invited to take part in an interview session. Ethical committees in the participating countries provided approval for the study.

**Data**

Data collection consisted of two parts: the first part was a written questionnaire with validated measures recording demographic variables and participation in local organisations. The second part was a pre-structured face-to-face or telephone interview, focussing on social networks and social support. We chose interviews for the social network questions, based on pilot testing in 25 diabetes patients, which showed that written surveys of these measures were not feasible in the targeted population.

**Individual demographic measures**

Low SES was defined by the presence of a combination of a low education and a low income. Low education was defined as an education up to secondary school, whereas college and university were defined as high education. We measured income relative to the country’s average income. Respondents answered whether their income was below / about / above the country yearly average income (BG 4,500 lev; GR 12,000 EUR; NL 33,000 EUR; NO 350,000 NKr.; ES 22,800 EUR;
UK 25,000 pound). Low income was defined as income below the country yearly average income for each country. Besides SES, country of birth of the parents, and a short list of nine comorbidities were assessed.

**Social network measures**

Data on the number of household members, presence of spouses and participation in community organisations were gathered using structured questions. Participating in community organisations was defined as visiting a community group, activity or service from a community group at least once a month within the last 6 months. Data on individual support networks was collected through interviews using a validated name generator method in which participants were asked to generate a list of persons that were valuable to them. This method first requires a respondent to name actual persons and then several additional questions about these individuals are asked. For each individual mentioned through the name generator additional data were gathered, such as age, gender, type of relationship with the respondent, the type of support (informational, practical or emotional) provided by that member, and whether network members knew each other. Informational support was defined as exchanging information related to dealing with someone's illness; practical support as providing help with practical things in and around the house; and emotional support was defined as talking about health problems or other personal issues. Network members were divided into three types: family members, non-family members (friends, neighbours), and healthcare professionals. Finally, the position generator was used to identify access to specified professionals (nurse, doctor or pharmacist). This method measures access to people with specific occupations and could function as a source for social capital. Unlike the patient's self-reported support network, which only included close members, the professionals identified through the position generator could be part of the patient's wider environment, beyond close network members. However, we restricted these contacts to friends and family members.

**Network structure parameters**

Structural network parameters were derived from the network composition. Density was calculated as the number of present ties compared to the maximum possible amount of ties in an ego network. The proportion of closed triads was calculated as the number of possible combinations of three network members that know each other divided by the maximum number of possible combinations of three network members in a network. Due to the nature of this measure, this proportion was only applicable to networks with at least two support members. Multiplexity was measured as the overlap in support (emotional, practical, and informational) within a single network member. A network member was considered not multiplex (score 0) when he/she provided only one type of support, medium multiplex (score 0.5) when providing support in two domains, and maximum multiplex (score 1) when he/she provided support on all
three domains. The observed overlap per network member was averaged over the number of network members in a patients' network.

**Volume of generated social support**

Indicators of social support were generated in the network through the use of different measures. First, we calculated the total number of members of the support network, i.e., the size of someone’s network which could vary from 0 to 7 network members. Second, we measured for each type of support how much support each network member provided. Network members were considered to provide support across three different domains; informational support, practical support, and emotional support. For each type of support, the amount of support per network member could vary from no support provided (value 0), some support provided (value 0.5), and a lot of support provided (value 1). Thus, the total amount of support per network member could vary from 0 to 3. We calculated the total amount of support as the sum of the three different types of support resulting in a range from 0 (no support at all) to 21 (a lot of support by all 7 network members in every type of support). This total amount of support was also calculated for every domain, creating a range from 0 to 7 for each type of support.

**Statistical analysis**

First, we compared network characteristics between high and low SES groups. P-values were calculated using multilevel models with respondents nested within areas, and areas within countries. Secondly, we tested which network characteristics had an influence on the amount of support generated in a network. We used multilevel regression models (patients nested within countries) with the amount of support as outcome and network characteristics as independent variables. We controlled for the individual patient characteristics, age, sex, having parents born abroad, comorbidities, and neighbourhood. In addition, we also related the size of a network, the amount of support provided per network member, and if a network member provides support on multiple domains (multiplexity) to each other to check how they are interrelated. To account for missing values in the data we applied a multiple imputation procedure. In addition, we plotted the relation between total amount of support versus network size and amount of support per network member. Due to a high correlation between some of these measures and consequent collinearity problems, we were not able to use all measures in the regression models. When collinearity arose, the measure that correlates highest with the amount of support was chosen.

**RESULTS**

In total, 1,861 patients completed the written questionnaire, of which 1,692 participated in the interview. The average age was 66.1 years, men and women were equally present (50.0% female) and overall 6% had parents who were born abroad, as shown in table 1.
Table 1. Patient characteristics

<table>
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<tbody>
<tr>
<td>Sex (% female)</td>
<td>50.0</td>
<td>61.1</td>
<td>57.3</td>
<td>43.8</td>
<td>38.5</td>
<td>55.9</td>
<td>40.0</td>
</tr>
<tr>
<td>Age in years (mean)</td>
<td>66.2</td>
<td>65.2</td>
<td>69.0</td>
<td>68.4</td>
<td>59.8</td>
<td>69.3</td>
<td>65.5</td>
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<td>Parents born in other country (%)</td>
<td>6.3</td>
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<td>8.6</td>
<td>13.9</td>
<td>14.4</td>
<td>1.0</td>
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</tr>
<tr>
<td>Retired (%)</td>
<td>62.3</td>
<td>70.9</td>
<td>72.7</td>
<td>60.6</td>
<td>29.7</td>
<td>75.3</td>
<td>64.4</td>
</tr>
<tr>
<td>Low SES (income and education)</td>
<td>43.6</td>
<td>23.6</td>
<td>47.2</td>
<td>36.0</td>
<td>28.7</td>
<td>75.2</td>
<td>41.4</td>
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<tr>
<td>Comorbidities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 comorbidities</td>
<td>14.8</td>
<td>7.4</td>
<td>7.6</td>
<td>13.5</td>
<td>15.1</td>
<td>19.3</td>
<td>26.3</td>
</tr>
<tr>
<td>1-2 Comorbidities</td>
<td>57.4</td>
<td>52.7</td>
<td>60.6</td>
<td>61.2</td>
<td>51.2</td>
<td>59.7</td>
<td>59.4</td>
</tr>
<tr>
<td>&gt; 2 Comorbidities</td>
<td>27.8</td>
<td>39.9</td>
<td>31.8</td>
<td>25.3</td>
<td>33.7</td>
<td>21.0</td>
<td>14.2</td>
</tr>
<tr>
<td>Neighbourhood</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban deprived</td>
<td>35.9</td>
<td>35.3</td>
<td>32.8</td>
<td>37.6</td>
<td>35.4</td>
<td>33.1</td>
<td>42.3</td>
</tr>
<tr>
<td>Urban affluent</td>
<td>39.1</td>
<td>32.2</td>
<td>32.8</td>
<td>21.6</td>
<td>30.6</td>
<td>32.8</td>
<td>57.7</td>
</tr>
<tr>
<td>Rural deprived</td>
<td>25.0</td>
<td>32.5</td>
<td>34.4</td>
<td>40.8</td>
<td>34.0</td>
<td>34.1</td>
<td></td>
</tr>
</tbody>
</table>

* Not recorded; † Not included in sampling

Network characteristics

Table 2 shows the network characteristics of our respondents, overall and separately for low and high SES groups. The average size of a support network was 3.21 and was not different between high and low SES groups. The average density was 0.89, indicating that most of the network members knew each other. The mean multiplexity score was 0.50, with the most people performing two support tasks (0.38) and a smaller proportion performing one or three tasks (0.30 and 0.28 respectively). The proportion of closed triads was 0.81 and about 70% had a spouse, with a clear difference between SES groups; 65.8% in the low SES group versus 74.5% in the high SES group. Networks consisted predominantly of family members with nearly 2 members forming a proportion of 0.62. Furthermore, an average network had 0.49 non-family members such as friends and neighbours and 0.75 professional health providers. Women constituted a larger proportion of support networks with an average of 0.63. Although the proportion did not differ between high and low SES groups, high SES groups had slightly more (1.90 versus 1.77) women in their support networks. Looking at respondent's wider network, we saw that half of them had a healthcare professional as a friend of family member. However, this was much higher in the high SES group (57.0%) than in the low SES group (37.4%). Finally, 34.6% of the respondents participated in community organisations.
Table 2. Network characteristics by SES

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Low SES</th>
<th>High SES</th>
<th>Δ Low vs High SES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>S.D.</td>
<td>Mean</td>
<td>S.D.</td>
</tr>
<tr>
<td>Size of the network (0-7)</td>
<td>3.21</td>
<td>1.78</td>
<td>3.09</td>
<td>1.75</td>
</tr>
<tr>
<td>Density</td>
<td>0.89</td>
<td>0.18</td>
<td>0.90</td>
<td>0.18</td>
</tr>
<tr>
<td>Multiplicity (average tasks)</td>
<td>0.50</td>
<td>0.18</td>
<td>0.52</td>
<td>0.32</td>
</tr>
<tr>
<td>1 support task (mean proportion)</td>
<td>0.28</td>
<td>0.34</td>
<td>0.26</td>
<td>0.33</td>
</tr>
<tr>
<td>2 support tasks (mean proportion)</td>
<td>0.38</td>
<td>0.36</td>
<td>0.38</td>
<td>0.36</td>
</tr>
<tr>
<td>3 support tasks (mean proportion)</td>
<td>0.30</td>
<td>0.36</td>
<td>0.31</td>
<td>0.37</td>
</tr>
<tr>
<td>Closed triads (proportion)</td>
<td>0.81</td>
<td>0.30</td>
<td>0.83</td>
<td>0.28</td>
</tr>
<tr>
<td>Spouse (% yes)</td>
<td>70.5</td>
<td>65.8</td>
<td>74.5</td>
<td>**</td>
</tr>
<tr>
<td>N family members</td>
<td>1.96</td>
<td>1.48</td>
<td>1.92</td>
<td>1.46</td>
</tr>
<tr>
<td>N non-family members</td>
<td>0.49</td>
<td>0.91</td>
<td>0.42</td>
<td>0.84</td>
</tr>
<tr>
<td>N professional members</td>
<td>0.75</td>
<td>0.86</td>
<td>0.74</td>
<td>0.86</td>
</tr>
<tr>
<td>Proportion family members</td>
<td>0.62</td>
<td>0.34</td>
<td>0.63</td>
<td>0.34</td>
</tr>
<tr>
<td>N women</td>
<td>1.85</td>
<td>1.17</td>
<td>1.77</td>
<td>1.21</td>
</tr>
<tr>
<td>N men</td>
<td>1.17</td>
<td>1.08</td>
<td>1.14</td>
<td>1.07</td>
</tr>
<tr>
<td>Proportion women</td>
<td>0.63</td>
<td>0.31</td>
<td>0.62</td>
<td>0.33</td>
</tr>
<tr>
<td>Healthcare professional in wider network (% yes)</td>
<td>49.7</td>
<td>37.4</td>
<td>57.0</td>
<td>**</td>
</tr>
<tr>
<td>Participating in community organisations (%)</td>
<td>34.6</td>
<td>35.9</td>
<td>34.0</td>
<td></td>
</tr>
</tbody>
</table>

* p<0.05, ** p<0.01

Generated support

Table 3 shows that the total amount of support in a network was 4.65 and was slightly higher in high SES groups (4.55 versus 4.69). The average number of network members was 3.21 and average support per network member was 1.49. Neither varied significantly between SES groups, however the size of the network seemed more responsible for the (significant) difference in total amount of support. Patients received most emotional support (2.01), followed by informational support (1.50) and practical support (1.13). The amount of emotional support was higher in high SES group than in low SES group (2.08 and 1.93 respectively).

Table 3. Social support characteristics by SES

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Low SES</th>
<th>High SES</th>
<th>Δ Low vs High SES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>S.D.</td>
<td>Mean</td>
<td>S.D.</td>
</tr>
<tr>
<td>Total support (0-21)</td>
<td>4.65</td>
<td>3.19</td>
<td>4.55</td>
<td>3.31</td>
</tr>
<tr>
<td>Size of the network (0-7)</td>
<td>3.21</td>
<td>1.78</td>
<td>3.09</td>
<td>1.75</td>
</tr>
<tr>
<td>Support per network member (0-3)</td>
<td>1.49</td>
<td>0.69</td>
<td>1.50</td>
<td>0.72</td>
</tr>
<tr>
<td>Information (0-7)</td>
<td>1.50</td>
<td>1.29</td>
<td>1.47</td>
<td>1.35</td>
</tr>
<tr>
<td>Practical (0-7)</td>
<td>1.13</td>
<td>1.06</td>
<td>1.14</td>
<td>1.07</td>
</tr>
<tr>
<td>Emotional (0-7)</td>
<td>2.01</td>
<td>1.49</td>
<td>1.93</td>
<td>1.48</td>
</tr>
</tbody>
</table>

* p<0.05, ** p<0.01
Figure 1 shows the relation between the size of someone’s network versus the total amount of received support and the support provided per network member. The curve was estimated by a regression model which included the main effect (network size) and the square of the main effect to check for nonlinearity. We see that the main effect of network size on total support slightly diminishes when patients have larger networks (main effect beta = 1.05, p < 0.01, squared beta = -0.36, p < 0.01). Although the effect diminishes, the total amount of support still increased up to the (maximum) network size of 7. Network size and the support per network member were negatively correlated and this effect became stronger when network size grew (main effect beta = 0.10, squared beta = -0.23, p < 0.05). The average support per network member in networks with only one member was 1.52 and this decreased to 1.25 for networks with seven network members. These figures indicated that larger networks generate more support, but the amount of support per individual network member decreases.

**Figure 1. Total support and support per network member versus network size**

Individual and network characteristics associated with social support

Looking at the impact of individual characteristics on the total volume of social support, we found that the volume of support in patient’s network was higher for women (beta = 0.10) (Table 4, first column). With regard to network characteristics, the proportion of family members (beta = 0.15), having a spouse (beta = 0.07), having a healthcare professional in the wider network (beta = 0.09), and participating in community organisations (beta = 0.05) were positively related to the amount of provided support.

When we break these effects down into the size of a network and the provided support per network member (Table 4, second and third column), we found that the effect of sex is largely due to the number of network members (beta = 0.09) and not to the amount of support generated per network member (beta = 0.01). Respondents living in a rural deprived area received more support per network member compared to respondents living in an urban affluent area (beta = 0.16), however the total volume of support did not differ significantly between both groups. Low SES groups had relatively smaller networks (beta = -0.06), but for the total amount
of support and the amount of support per network member there was no significant difference. The positive effect of the proportion of family members was attributed to both the size and the amount of support per network member (both beta = 0.16). A larger proportion of women in a network was negatively related to the size of a network (beta = -0.10), but positively to the amount of support per network member (beta = 0.11) resulting in no effect on the total amount of support. The positive effect of having a healthcare provider was largely based on the greater amount of support per network member (beta = 0.08) and the effect of participating in community organisations mostly on the larger size (beta = 0.07) of those networks. Finally, the support provided per network member seemed to decrease when networks become larger (beta -0.07).

Table 4. Effects of individual and network characteristics on total support (beta’s)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total support</th>
<th>Size (0-7)</th>
<th>Support per network member</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>0.00</td>
<td>0.02</td>
<td>-0.03</td>
</tr>
<tr>
<td>Sex (ref: male)</td>
<td>0.10 **</td>
<td>0.09 **</td>
<td>0.01</td>
</tr>
<tr>
<td>Parents born in other country</td>
<td>0.00</td>
<td>-0.01</td>
<td>0.00</td>
</tr>
<tr>
<td>Comorbidities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2 Comorbidities</td>
<td>0.01</td>
<td>-0.01</td>
<td>0.00</td>
</tr>
<tr>
<td>&gt; 2 Comorbidities</td>
<td>0.04</td>
<td>-0.02</td>
<td>0.05</td>
</tr>
<tr>
<td>Neighbourhood (urban affluent = ref.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban deprived</td>
<td>0.06</td>
<td>0.09</td>
<td>-0.03</td>
</tr>
<tr>
<td>Rural deprived</td>
<td>0.06</td>
<td>-0.02</td>
<td>0.16 **</td>
</tr>
<tr>
<td>Low SES</td>
<td>-0.05</td>
<td>-0.06 *</td>
<td>-0.02</td>
</tr>
<tr>
<td>Proportion family members</td>
<td>0.15 **</td>
<td>0.16 **</td>
<td>0.16 **</td>
</tr>
<tr>
<td>Proportion women</td>
<td>-0.03</td>
<td>-0.10 **</td>
<td>0.11 **</td>
</tr>
<tr>
<td>Spouse (% yes)</td>
<td>0.07 **</td>
<td>0.04</td>
<td>0.04 *</td>
</tr>
<tr>
<td>Healthcare professional in wider network (%)</td>
<td>0.09 **</td>
<td>0.02</td>
<td>0.08 **</td>
</tr>
<tr>
<td>Participating in community organisations (%)</td>
<td>0.05 *</td>
<td>0.07 **</td>
<td>0.01</td>
</tr>
<tr>
<td>Multiplexity (average tasks)</td>
<td></td>
<td>-0.05</td>
<td></td>
</tr>
<tr>
<td>Density</td>
<td></td>
<td></td>
<td>0.05</td>
</tr>
<tr>
<td>Size</td>
<td></td>
<td></td>
<td>-0.07 **</td>
</tr>
<tr>
<td>Adjusted R-square</td>
<td>0.03</td>
<td>0.07</td>
<td>0.11</td>
</tr>
</tbody>
</table>

* p<0.05, ** p<0.01

Examining the types of support separately, we found that individual characteristics had little influence (Table 5). Only in terms of emotional support did women receive more support (beta = 0.15) and lower SES groups receive less support (beta = -0.08). Network characteristics were more strongly related to the different types of support. The proportion of family members in a patient’s network was negatively related to the amount of received informational support (beta = -0.011), however positively to the amount of practical (beta = 0.27) and emotional (beta = 0.22) support. Having a spouse was related to more informational (beta = 0.09) and emotional (beta = 0.05) support. The presence of a healthcare professional in someone’s wider network was related
to more support in all domains (beta informational = 0.11, practical = 0.05, and emotional = 0.05). Finally, participating in a community organisation was positively associated with more informational and emotional support (both beta = 0.06).

Table 5. Effects of individual and network characteristics on amount of support per type (beta’s)

<table>
<thead>
<tr>
<th></th>
<th>Informational support</th>
<th>Practical support</th>
<th>Emotional support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-0.02</td>
<td>0.02</td>
<td>0.00</td>
</tr>
<tr>
<td>Sex (ref: male)</td>
<td>0.05</td>
<td>0.03</td>
<td>0.15 **</td>
</tr>
<tr>
<td>Parents born in other country</td>
<td>-0.02</td>
<td>0.02</td>
<td>0.00</td>
</tr>
<tr>
<td>Comorbidities</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2 Comorbidities</td>
<td>-0.01</td>
<td>0.02</td>
<td>0.03</td>
</tr>
<tr>
<td>&gt; 2 Comorbidities</td>
<td>0.03</td>
<td>0.04</td>
<td>0.03</td>
</tr>
<tr>
<td>Neighbourhood (urban affluent = ref.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban deprived</td>
<td>0.07</td>
<td>0.03</td>
<td>0.04</td>
</tr>
<tr>
<td>Rural deprived</td>
<td>0.08</td>
<td>0.02</td>
<td>0.05</td>
</tr>
<tr>
<td>Low SES</td>
<td>-0.02</td>
<td>-0.01</td>
<td>-0.08 **</td>
</tr>
<tr>
<td>Proportion family members</td>
<td>-0.11 **</td>
<td>0.27 **</td>
<td>0.22 **</td>
</tr>
<tr>
<td>Proportion women</td>
<td>0.01</td>
<td>-0.03</td>
<td>-0.04</td>
</tr>
<tr>
<td>Spouse (% yes)</td>
<td>0.09 **</td>
<td>0.04</td>
<td>0.05 *</td>
</tr>
<tr>
<td>Healthcare professional in wider network (%)</td>
<td>0.11 **</td>
<td>0.05 *</td>
<td>0.05 *</td>
</tr>
<tr>
<td>Participating in community organisations (%)</td>
<td>0.06 *</td>
<td>0.00</td>
<td>0.06 *</td>
</tr>
<tr>
<td>Adjusted R-square</td>
<td>0.09</td>
<td>0.02</td>
<td>0.04</td>
</tr>
</tbody>
</table>

* p<0.05, ** p<0.01

DISCUSSION

Main findings

In considering the structural characteristics of support networks of diabetes patients we found that social support networks are often characterised by their relatively small size (just over 3 members) with members that often knew each other. Family members constituted the largest element of network membership with women being overrepresented. These network members provided support in multiple domains. A third of all individuals with a long term condition (egos) participated in a community organisation. The high SES group more often had a spouse and a healthcare professional as a friend or family member in their wider network. Also they received slightly more support than the low SES group especially emotional support. Emotional support was nearly provided at twice the rate as practical support, while informational support was situated in-between. Overall, differences between SES groups on network characteristics were relatively small.

In exploring the associations between network structure characteristics, we found that larger networks are associated with more overall support than smaller ones, but with a non-linear, declining relationship; as network size grew, the amount of support per network member declined. This was confirmed by the diminishing effect of support per network member in larger networks, where network members provide less support to an individual person. This indicates
that in smaller networks a network member provides more support than in larger networks. Such a network could be more efficient, but network members may also experience a greater burden of care and higher risk of drop-out. If we want to reduce the burden for network members, enlarging the support network could achieve this. Increasing network size may result in more support when new members provide diverse input, such as different diet habits, and thus increasing the quality of the network.

In terms of network characteristics we found that the higher the proportion of family members present in a network the more likely it was that the total amount of support would be greater, both in terms of size and support per member. This indicates that good family ties are beneficial to creating and maintaining a well supporting network. However, non-family links to healthcare providers and community organisations were also linked to the provision of extra support.

In relation to the presence of the different types of support, we found that a support network with a higher proportion of family members generated less informational support, but more practical and emotional support than those with fewer or no such members. Having a spouse, having a healthcare professional as a friend of family member, and participating in community organisations all resulted in more support, and especially informational type of support.

**Embedding in literature**

The declining effect of network size on total support may emanate as a consequence from the burden of the work that people with diabetes have to undertake in order to maintain a larger network. Living with a long term condition whilst sustaining ties with many and diverse relationships is not a simple task. Previous studies have shown that negotiating network relationships is an important and consuming task in support networks for diabetes patients. The imbalance in gender representation in support networks has been found in other studies as well. These studies explained this as a difference in the female/male world view dichotomy based on socialisation effects, where women seek more support from friends and extended family while men seek more support from their spouse. The relation between low SES and emotional support was also found in a study showing that low levels of income and education were both associated with lower levels of emotional support. The lack of an effect of density could be due to dense networks being linked to poor access to different information sources and a high redundancy in information. This study also showed that individuals who lived in rural settings had more social support than those in urban areas, which resembles the higher amount of support per network member in rural areas in our present study.

**Strengths and limitations**

An important feature of this study is the comprehensive data collection in six European countries in which all respondents were interviewed about their social support network. This method of data collection added to the validity of our findings and the variety of countries increased the relevance for multiple settings throughout Europe. A limitation is the high correlation between
some of the network characteristics and amount of support. This correlation made it impossible to test all relationships simultaneously and limits the possibility to draw conclusions about the effect of structural network characteristics on the amount of support. Also, because of the cross-sectional design of this study, we only studied associations and not causal relationships. Therefore, we cannot be sure if a change in network characteristics would have the same effect on amount of support.

**Implications for practice**

The non-linear association between network size and the total volume of social support suggests that there is an optimum size for a network. Larger networks result in less support per network member. Therefore, increasing network size may not always result in more overall support and interventions to enlarge someone's network should take this into consideration. If, however, the goal is to reduce the burden for network members, enlarging a network could be a successful intervention. A potential effective way to enhance the support network of type 2 diabetes patients is by motivating them to join a community organisation\(^{34}\). Participating in a community organisation was associated with more overall support and can be effective in improving health outcomes\(^{20,35}\).
REFERENCES

Chapter 6

Social support and health in diabetes patients: an observational study in six European countries in an era of austerity

Jan Koetsenruijter
Jan van Lieshout
Christos Lionis
Maria Carmen Portillo
Ivo Vassilev
Elka Todorova
Christina Foss
Manuel Serrano Gil
Ingrid Ruud Knutsen
Agapi Angelaki
Agurtzane Mujika
Poli Roukova
Anne Kennedy
Anne Rogers
Michel Wensing

ABSTRACT

Introduction: Support from individual social networks, community organisations and neighbourhoods is associated with better self-management and health outcomes. This international study examined the relative impact of different types of support on health and health-related behaviours in patients with type 2 diabetes.

Methods: Observational study (using interviews and questionnaires) in a sample of 1,692 type 2 diabetes patients with 5,433 connections from Bulgaria, Greece, Netherlands, Norway, Spain, and the United Kingdom. Outcomes were patient-reported health status (SF-12), physical exercise (RAPA), diet and smoking (SDCSCA). Random coefficient regression models were used to examine linkages with individual networks, community organisations, and neighbourhood type (deprived rural, deprived urban, or affluent urban).

Results: Patients had a median of 3 support connections and 34.6% participated in community organisations. Controlled for patients' age, sex, education, income and comorbidities, large emotional support networks were associated with decrease of non-smoking (OR = 0.87). Large practical support networks were associated with worse physical and mental health (B = -0.46 and -0.27 respectively) and less physical activity (OR = 0.90). Participation in community organisations was associated with better physical and mental health (B = 1.39 and 1.22, respectively) and, in patients with low income, with more physical activity (OR =1.53).

Discussion: Participation in community organisations was most consistently related to better health status. Many diabetes patients have individual support networks, but this study did not provide evidence to increase their size as a public health strategy. The consistent association between participation in community organisations and health status provides a clear target for interventions and policies.
INTRODUCTION
Self-management is a key component of the management of many long-term conditions, including type 2 diabetes. Ageing populations and unhealthy lifestyles are attributed with responsibility for an increase in the prevalence of these conditions. For example, in the European Union, about 53 million adults aged 20–79 years had diabetes in 2013 and this is predicted to increase to 64 million in 2030\textsuperscript{1}. As part of recent austerity measures in recent years, public services have increasingly made chronic-disease patients responsible for the management of their own health. This transfer of responsibility has greatest impact on patients with low incomes, as austerity measures affect them more than affluent groups and they also have the capacity to benefit most from self-management support\textsuperscript{2–4}. These developments have increased the burden on individual patients with long term conditions and raise the question whether all patients receive the support they need to manage their health and diseases.

Although self-management has often been defined in terms of individual competencies, its effectiveness is increasingly perceived to be influenced by social support\textsuperscript{5–7}. Social support for patients with chronic diseases is help provided by family, friends, neighbours or others; it includes different domains, such as information, emotional comfort, and practical help. This support is provided through individual social networks with family and friends, but also in community organisations and local neighbourhoods. Social support may function as a compensation for austerity measures as previous research found that large and varied individual social networks were associated with better health outcomes\textsuperscript{8,9}. Different mechanisms relating to how networks can affect health have been identified. Individual networks can help the patient to navigate individuals to available sources of support and influence the coordination of support activities\textsuperscript{10,11}. Contagion of ideas and behaviours has been suggested to explain the impact of being embedded in a group or population, such as a community organisation\textsuperscript{12}. Also, neighbourhoods can influence population health by their physical and social lay out\textsuperscript{13}.

Within individual countries, some indication is given how the social context can contribute to better health. A study in the UK suggests that community and network-centered approaches may be particularly relevant for engaging people in socially and economically deprived areas\textsuperscript{7}. Another study in the United Kingdom explored social support systems of people with diabetes\textsuperscript{14}. In Norway, poor social integration among elderly was related to higher mortality\textsuperscript{15}, and in the Netherlands poor emotional support was related to higher mortality\textsuperscript{16}. In Spain a study found that among elderly a low social network was related to more hospital admissions\textsuperscript{17} and that social support offered protection against the adverse effect of economic recessions on mental health\textsuperscript{18}. However, most of these studies focused on single factors and single settings and therefore it is unclear what the relative impact of different aspects of support on health is.

In this international study, we aimed to describe the social support available to patients with type 2 diabetes and to identify which aspects of social support are related to health and health-related behaviours in patients with type 2 diabetes in a variety of European countries. Moreover, we investigated whether these relationships differ between high and low income groups, in order to
explore whether social support can compensate for the adverse health effects of deprivation and austerity.

METHODS
Study design, setting and participants
We conducted an international cross-sectional study in patients with type 2 diabetes. Data were collected as part of the EU-WISE project which is an European project based on the WISE (Whole System Informing Self-management Engagement) approach and was funded by the European Union Seventh Framework Programme (FP7) Health\textsuperscript{19,20}. The study was conducted in 18 purposefully chosen geographic areas in 6 countries, which reflect a variety of health and welfare systems: Bulgaria, Greece, the Netherlands, Norway, Spain, and the UK. Patients were recruited through healthcare practices. Each of the participating countries selected a deprived urban area; a relatively affluent urban area; and a deprived rural area (relative to country). We defined urban as located in a city with more than 100,000 inhabitants and rural as located in towns or villages with fewer than 30,000 inhabitants. This selection of areas (rather than a random sample) allowed us to study both individual and area characteristics. Because the areas were chosen purposefully and not randomly, the areas are not necessarily representative for the countries involved. In each area, 100 patients with a medical diagnosis of type 2 diabetes were recruited resulting in about 300 patients in each country. This number allowed us to detect a medium effect size ($r^2 = 0.15$) based on $\alpha = 0.05$, intraclass correlation coefficient (ICC) = 0.03, power = 0.80 and the inclusion of eight independent variables in the analysis\textsuperscript{19,21}. Inclusion criteria were: medical diagnosis of diabetes; type 2 diabetes only; age of 18 years or over. Exclusion criteria were: pregnancy; pregnancy-related diabetes; recent/current major surgery or medical procedures; severe cognitive or psychiatric handicap; terminal illness/receiving palliative care; absence of translators (e.g. family members) for patients with insufficient language skills. Eligible patients were given an invitation letter with information, a consent form, and a written questionnaire via their healthcare practice. Patients who completed the questionnaire were invited to participate in an interview as well. Written informed consent was given by all patients. Ethical committees in the different countries provided approval for the study; The UNWE and the NCPHA (National Center for Public Health and Analysis) in Bulgaria, the Scientific & Bio-ethical Committee and the Administration Council of the Regional Academic Hospital (PAGNI) of Heraklion in Greece, the CMO region Arnhem Nijmegen in The Netherlands, the Regional Committee for Health and Research Ethics and the ethical committee of the Oslo University Hospital, the Ethics Commission of the University of Navarra, and the University of Manchester Research Ethics Committee, the Greater Manchester Research Ethics Committee, Salford and Trafford local research ethics committee, and the University of Southampton Ethics and Research Governance Online in the UK.
Measures

The study used a pre-structured patient questionnaire, which consisted of two parts: first a written questionnaire with validated measures recording demographic variables, quality of life, self-care behaviours, received care and participation in local organisations. The second part was a face-to-face or telephone interview, which focused on social networks and social support. The choice of interviews was based on pilot testing which suggested that written surveys of the measures were not feasible in the targeted population.

Social support measures: individual support networks and community organisations

Data on numbers of household members, presence of spouses and participation in community organisations were gathered using structured questions (3 items). Attending community organisations was based on the question which community groups, activities or services the respondent visited in the last 6 months. Examples of these groups could involve: well-being, internet communities, health education, practical support, healthy eating, physical activity or transport. Data on individual support networks was collected through interviews using a validated name generator method. This method first requires a respondent to name actual persons and then several additional questions about these individuals were asked. For each individual mentioned through the name generator, the following 9 items were derived: gender, age, type of relationship, duration of relationship, distance to member, and, the number of members that provided information, practical or emotional support. Information was defined as information related to dealing with someone’s illness; practical support as receiving help with practical things in and around the house; emotional support was defined as talking about health problems or other personal problems. Finally, the position generator was used to identify access to people with specified healthcare professions (nurse, doctor or pharmacist). This method measures access to network members’ occupations that functions as a source for social capital. These people were not necessarily part of the patient’s self-reported support network, as they could be in the patient’s wider environment, defined as all their friends and family members.

Other measures

We measured income relative to the country’s average income. Respondents answered whether their income was below/about/above the country yearly average income (BG 4,500 lev; GR 12,000 EUR; NL 33,000 EUR; NO 350,000 NKr.; ES 22,800 EUR; UK 25,000 pound). We defined low income as those whose income was below the country yearly average income. We regarded someone as non-native if one of the parents was born in a different country. In addition, a short list of 9 comorbidities was included.

Outcomes: health and health-related behaviours

We used the SF-12 (version 2) to measure functional health status, both a physical and mental component. The SF-12 was devised as a shortened version of the SF-36 which is a set of generic,
coherent, and easily self-administered health related quality-of-life measures, developed by RAND as part of the Medical Outcomes Study (MOS)\textsuperscript{26}. The physical (PCS) and mental (MCS) component are subsets of the SF-12. To assess self-management behaviour we used 3 indicators: physical activity, healthy diet and non-smoking. These indicators were measured by 2 validated scales: the Summary of Diabetes Self-Care Activities (SDSCA) and the Rapid Assessment of Physical Activity (RAPA). The SDSCA assesses self-care behaviour and lifestyle, including diet, smoking, physical exercise, blood sugar testing and foot care\textsuperscript{27}. The SDSCA was used for diet (2 items measuring general diet) and smoking. Non-smoking was defined as not having smoked a single cigarette in the preceding seven days and a healthy diet was defined as following a healthy eating plan for at least six days a week. The RAPA is used for a more detailed measurement of physical lifestyle of respondents. This questionnaire was specifically developed to measure the level of physical activity of older patients\textsuperscript{28}. Healthy physical activity was defined as; doing moderate physical activities at least 30 minutes a day, 5 or more days a week or; doing vigorous physical activities 20 minutes a day, 3 or more days a week. Although all measures were chosen based on proven validity and reliability and often already were translated into other languages, not all measures were available in all countries. Measures that were not yet available in all countries were translated into the specific language using forward- and back-translation and were culturally adapted to the specific country characteristics. In Bulgaria, the SCSCA, RAPA, and, SF-12 were translated independently by two researchers into the Bulgarian language. Consensus on the both translations was done by a third researcher and the final version of the translated questionnaire was translated back by a professional translator. The procedure for the heiQ translation followed the same procedure, and also included an extensive discussion with the developer of the heiQ (Richard Osborn, Deakin University), so that the Bulgarian team and UK team received an official license to use in Bulgaria. In Greece, the RAPA was translated by three researchers and a professional translator independently. After reaching consensus, back translation was done by the same team and cultural adaptations were made. The newly translated questionnaire was pilot tested in 3 diabetes type 2 patients in order to test clarity and understanding.

**Statistical analysis**

We calculated descriptives per country of patient characteristics with measures for individual characteristics and social support characteristics. The same descriptives were presented for the measures of self-management (physical activity, diet and smoking) and physical and mental health status.

To determine the effect of social support on self-management we performed a regression analysis with self-management and health status as dependent variables and individual and social support characteristics as independent variables. Physical and mental health status were treated as interval scale and therefore analyzed using an ordinary least squares (OLS) linear regression model; physical activity, diet and smoking were dichotomised and therefore analyzed using a
logistic regression model. The regression analyses were based on a multilevel model with a random slope with patients nested within areas and both nested in the six participating countries\(^29\). All analyses were controlled for patients' age, gender, comorbidity and educational background as potential confounders.

We first tested the effects of income and social support for the whole sample. Secondly, we performed the same analysis separately for high and low income groups, to identify if the effects (e.g. of social networks on self-management behaviours) were different between level of deprivation. All regression analyses were performed for each country separately to check for patterns within countries. Countries and areas were not randomly sampled, and therefore both levels were considered fixed factors implying that generalisation beyond chosen areas and countries was avoided. Significance was indicated by \(p < 0.05\) and analyses were performed using IBM SPSS statistics 20 (IBM Corp.) and MLwiN 2.28 (Centre for Multilevel Modelling).

**RESULTS**

In total, 1,861 patients completed the written questionnaire, of which 1,692 also participated in the interview. Average age was 66.2 year, men and women were equally present (50.0% female) and 6.2% had a non-native origin. The majority (61.0%) had an income that was below the country average, which reflects the focus of the study on deprived populations. They reported 5,433 connections with individuals providing some kind of support (a mean of 3.2 connections per patient and a median of 3 connections per patient). Nearly half (48.3%) had health professionals in their extended network and about a third (34.6%) participated in community organisations. Regarding self-management behaviour, a physically-active lifestyle was reported by 35.3%, 50.8% followed a healthy diet and 85.8% were non-smokers (Table 1).

**Table 1. Description of patient samples**

<table>
<thead>
<tr>
<th>Individual characteristics</th>
<th>Total (n=1,692)</th>
<th>Bulgaria (n=283)</th>
<th>Greece (n=302)</th>
<th>Netherlands (n=245)</th>
<th>Norway (n=291)</th>
<th>Spain (n=290)</th>
<th>UK (n=281)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (% female)</td>
<td>50.0</td>
<td>61.1</td>
<td>57.3</td>
<td>43.8</td>
<td>38.5</td>
<td>55.9</td>
<td>40.0</td>
</tr>
<tr>
<td>Age in years (mean)</td>
<td>66.2</td>
<td>65.2</td>
<td>69.0</td>
<td>68.4</td>
<td>59.8</td>
<td>69.3</td>
<td>65.5</td>
</tr>
<tr>
<td>Parents born in other country (%)</td>
<td>6.3</td>
<td>0.4</td>
<td>8.6</td>
<td>3.9</td>
<td>14.4</td>
<td>1.0</td>
<td>-</td>
</tr>
<tr>
<td>Pet in household (% yes)</td>
<td>38.0</td>
<td>55.0</td>
<td>53.5</td>
<td>29.1</td>
<td>30.7</td>
<td>30.5</td>
<td>27.3</td>
</tr>
<tr>
<td>Education (mean years)</td>
<td>10.3</td>
<td>10.5</td>
<td>7.8</td>
<td>11.0</td>
<td>11.1</td>
<td>9.0</td>
<td>12.7</td>
</tr>
<tr>
<td>Pensioner (%)</td>
<td>62.3</td>
<td>70.9</td>
<td>72.7</td>
<td>60.6</td>
<td>29.7</td>
<td>75.3</td>
<td>64.4</td>
</tr>
<tr>
<td>Low income</td>
<td>61.0</td>
<td>69.3</td>
<td>55.5</td>
<td>47.5</td>
<td>46.2</td>
<td>81.1</td>
<td>65.6</td>
</tr>
<tr>
<td>Comorbidities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 comorbidities</td>
<td>14.8</td>
<td>7.4</td>
<td>7.6</td>
<td>13.5</td>
<td>15.1</td>
<td>19.3</td>
<td>26.3</td>
</tr>
<tr>
<td>1-2 Comorbidities</td>
<td>57.4</td>
<td>52.7</td>
<td>60.6</td>
<td>61.2</td>
<td>51.2</td>
<td>59.7</td>
<td>59.4</td>
</tr>
<tr>
<td>&gt; 2 Comorbidities</td>
<td>27.8</td>
<td>39.9</td>
<td>31.8</td>
<td>25.3</td>
<td>33.7</td>
<td>21.0</td>
<td>14.2</td>
</tr>
<tr>
<td>Physician/nurse visits last 6 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-2 visits</td>
<td>35.0</td>
<td>14.5</td>
<td>1.0</td>
<td>67.9</td>
<td>39.7</td>
<td>40.9</td>
<td>53.9</td>
</tr>
<tr>
<td>3-5 visits</td>
<td>51.4</td>
<td>56.0</td>
<td>93.7</td>
<td>29.2</td>
<td>45.2</td>
<td>43.0</td>
<td>34.9</td>
</tr>
<tr>
<td>&gt; 5 visits</td>
<td>13.5</td>
<td>29.4</td>
<td>5.3</td>
<td>2.9</td>
<td>15.2</td>
<td>16.1</td>
<td>11.2</td>
</tr>
</tbody>
</table>
Controlled for other patient characteristics and comorbidities, lower income was related to worse physical and mental health status (B = -1.87 and -1.38, respectively) (Table 2). Individual network characteristics were inconsistently related to physical quality of life. Having a spouse was associated with a better physical health status (B = 1.01), especially for patients with a high income, whereas receiving more practical support was associated with a worse physical health status (B = -0.46). Controlled for patients characteristics and comorbidities, attending community organisations was related to better physical health status (B = 1.39). Similar linkages were found for mental health status; having a spouse and visiting community organisations were related to better health status and practical support to worse health status (B = 0.88, 1.22, and -0.27, respectively). In addition, having more health professionals in the wider network was associated with better mental health status (B = 0.67), mostly for patients with a low income (B = 0.76). Patients living in an urban deprived area had worse mental health status compared to patients living in an urban affluent area (B = -0.84), but this effect was only present for patients with a low income (B = -1.29 versus B = -0.11 for high incomes). Effects per individual country are provided in Supplemental tables 1 till 5.
Table 2. Linear regression estimates (B) for the relation between social support and health status

<table>
<thead>
<tr>
<th></th>
<th>Physical health related QOL (SF-12)</th>
<th>Mental health related QOL (SF-12)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Overall multi-variate</td>
<td>Low income group</td>
</tr>
<tr>
<td>Age (10 year steps)</td>
<td>-0.44**</td>
<td>-0.18</td>
</tr>
<tr>
<td>Sex (male ref.)</td>
<td>-1.02**</td>
<td>-1.20**</td>
</tr>
<tr>
<td>Education</td>
<td>0.14**</td>
<td>0.16**</td>
</tr>
<tr>
<td>Non-native background</td>
<td>0.02</td>
<td>0.04</td>
</tr>
<tr>
<td>No comorbidities (ref.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2 Comorbidities</td>
<td>-2.30**</td>
<td>-1.82**</td>
</tr>
<tr>
<td>&gt; 2 Comorbidities</td>
<td>-4.87**</td>
<td>-4.72**</td>
</tr>
<tr>
<td>Low income</td>
<td>-1.87**</td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>1.01**</td>
<td>0.76</td>
</tr>
<tr>
<td>Household members</td>
<td>-0.09</td>
<td>-0.04</td>
</tr>
<tr>
<td>Support network members (N)</td>
<td>0.01</td>
<td>0.16</td>
</tr>
<tr>
<td>Network members providing:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information support</td>
<td>0.03</td>
<td>0.04</td>
</tr>
<tr>
<td>Practical support</td>
<td>-0.46**</td>
<td>-0.36*</td>
</tr>
<tr>
<td>Emotional support</td>
<td>0.13</td>
<td>0.04</td>
</tr>
<tr>
<td>Health professional in wider network</td>
<td>0.47</td>
<td>0.56</td>
</tr>
<tr>
<td>Attending community organisations</td>
<td>1.39**</td>
<td>1.32**</td>
</tr>
<tr>
<td>Neighbourhood (urban affluent = ref.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban deprived</td>
<td>-0.51</td>
<td>-0.49</td>
</tr>
<tr>
<td>Rural deprived</td>
<td>0.17</td>
<td>0.36</td>
</tr>
</tbody>
</table>

* p < 0.05; ** p < 0.01

Table 3 presents the analysis of health-related lifestyles. Lower income was related to less physical activity (OR = 0.75), but not to diet and smoking (Table 3). Regarding individual network characteristics higher number of practical support connections was associated with less physical activity. However, focusing on differences in level of income, the negative relationship between practical support connections and physical activity only applied to higher incomes (OR = 0.72), whereas for lower incomes no relation was found (OR = 1.00). Higher numbers of information and emotional support connections were related to more physical activity, however only for higher incomes (OR 1.20 and 1.30, respectively). Attending community organisations was positively related to physical activity, however only for patients with a low income (OR = 1.53). A healthy diet and non-smoking were less related to the social support indicators, with some exceptions. The number of household members was negatively associated with a healthy diet (OR = 0.91) and having a spouse was related to a more healthy diet in the high income group (OR = 1.67). Having more emotional support members in a network was negatively related to non-smoking (OR = 0.87). Living with more household members was positively associated with non-smoking, however only for the low income group (OR = 1.21) and attending community organisations was positively related to non-smoking, but only for higher incomes (OR = 1.72). Effects per individual country are provided in Supplemental tables 1 till 5.
Table 3. Logistic regression estimates (OR) for the relation between social support and health-related lifestyles

<table>
<thead>
<tr>
<th></th>
<th>Physical activity</th>
<th></th>
<th>Healthy diet</th>
<th></th>
<th>Non-smoking</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Overall multi-</td>
<td>Low income group</td>
<td>High income</td>
<td>Overall multi-</td>
<td>Low income</td>
<td>High income group</td>
</tr>
<tr>
<td></td>
<td>variate</td>
<td>group</td>
<td>group</td>
<td>variate</td>
<td>group</td>
<td>group</td>
</tr>
<tr>
<td>Age (10 year steps)</td>
<td>0.97</td>
<td>0.95</td>
<td>1.07</td>
<td>1.34**</td>
<td>1.41**</td>
<td>1.23*</td>
</tr>
<tr>
<td>Sex (male ref.)</td>
<td>0.63**</td>
<td>0.59**</td>
<td>0.73*</td>
<td>1.50**</td>
<td>1.63**</td>
<td>1.29</td>
</tr>
<tr>
<td>Education</td>
<td>1.04**</td>
<td>1.06**</td>
<td>1.01</td>
<td>1.05**</td>
<td>1.06**</td>
<td>1.04*</td>
</tr>
<tr>
<td>Non-native background</td>
<td>0.79</td>
<td>0.94</td>
<td>0.79</td>
<td>0.69*</td>
<td>0.95</td>
<td>0.48*</td>
</tr>
<tr>
<td>No comorbidities (ref.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2 Comorbidities</td>
<td>0.71*</td>
<td>0.63*</td>
<td>0.78</td>
<td>0.58**</td>
<td>0.59**</td>
<td>0.52**</td>
</tr>
<tr>
<td>&gt; 2 Comorbidities</td>
<td>0.40**</td>
<td>0.39**</td>
<td>0.41**</td>
<td>0.55**</td>
<td>0.55**</td>
<td>0.54*</td>
</tr>
<tr>
<td>Low income</td>
<td>0.75*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>1.07</td>
<td>1.09</td>
<td>1.19</td>
<td>1.05</td>
<td>0.90</td>
<td>1.67*</td>
</tr>
<tr>
<td>Household members</td>
<td>1.00</td>
<td>1.04</td>
<td>0.92</td>
<td>0.91*</td>
<td>0.90</td>
<td>0.92</td>
</tr>
<tr>
<td>Support network members (N)</td>
<td>0.92</td>
<td>1.04</td>
<td>0.77**</td>
<td>1.03</td>
<td>1.06</td>
<td>0.99</td>
</tr>
<tr>
<td>Network members providing:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information support</td>
<td>1.09*</td>
<td>1.01</td>
<td>1.20*</td>
<td>1.06</td>
<td>1.03</td>
<td>1.11</td>
</tr>
<tr>
<td>Practical support</td>
<td>0.90*</td>
<td>1.00</td>
<td>0.72**</td>
<td>1.03</td>
<td>0.99</td>
<td>1.08</td>
</tr>
<tr>
<td>Emotional support</td>
<td>1.10*</td>
<td>1.01</td>
<td>1.30**</td>
<td>0.96</td>
<td>1.00</td>
<td>0.92</td>
</tr>
<tr>
<td>Health professional in wider network</td>
<td>1.11</td>
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<td>1.44*</td>
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* p < 0.05; ** p < 0.01
DISCUSSION
This study found that across Europe patients with a diagnoses of diabetes reported variable availability of social support from individuals and community organisations. Participation in community organisations (reported by about a third of the population) was most consistently related to better health status and health-related behaviours, especially in low income populations. Individual support network characteristics had mixed effects on health and behaviours, while living in a deprived urban neighbourhood had a negative impact on mental health status. These linkages were influenced by individual income, which itself had a (positive) effect on health and health-related behaviours. In low income populations, some of the positive impacts of a large individual support network were not found.
Our findings are consistent with other studies that focus on the influences of social support and social networks. The mixed effect of individual support networks was also found in a systematic review which indicated tentative evidence for informal support. The contagion of health-related behaviours (such as smoking) as found by Fowler and Christakis in the Framingham cohort may have to be reconsidered, given our finding that some of the protective impacts of a large individual support network were only found in patients with high income. This suggests that deprived patients benefit less from a large network than those with high income. Regardless of the hypothesized mechanisms of social support, this finding raises important concerns about the potential untapped resources in individual networks to compensate for austerity measures, particularly in people with low income.
On the other hand, participation in community organisations had a consistently (small) positive effect on health status and physical activity, especially in low income groups. Besides directly providing information, practical help and emotional support, or navigating to sources of support, these organisations can fulfill a range of functions including enhancing feelings of social integration and individual identity. An alternative explanation for this relation between physical health and community organisations could be that a poor physical health resulted in less community organisations visits, suggesting a different causality. However, if a good physical health allowed patients to visit a community organisation, one would expect that this association was found in both the high and low income groups. Interestingly, qualitative interviews with individuals with diabetes suggested that providing support to others was one of the key mechanisms of support that contributed to better health status.
A strong and novel aspect of this study is that the involved multiple settings that reflect a variety of European countries. Moreover, these countries differ in health and welfare systems and policies in response to austerity in Europe. The focus on regions made it possible to combine various types of social support (from individual networks, community organisations, and neighbourhoods) in one analysis. The cross-sectional design of the study did not allow causal inferences, so we could only speculate about mechanisms underlying social support. While we used previously validated measures and methods, the study has a risk of bias due to non-identified differences in national health systems and cultures.
Further research could explore how different types of social support networks differ between patient characteristics such as gender, age, and income level. More inside in the differences between groups could provide an indication of the potential to increase social support networks. Some indication is provided by a study in the UK showing that non-white and more affluent participants received slightly higher amounts of everyday work support, however effects on illness related and emotional support were not found\textsuperscript{35}. Also it is known that women have larger and more supportive networks than men\textsuperscript{36}. However, interventions to improve social support found mixed results; a review on social support interventions could not clarify which aspects of social support were most effective for enhancing self-management and outcomes of care for people with type 2 diabetes\textsuperscript{37}. Therefore, more research on the development of successful interventions targeting social support is necessary and this study provides an indication for directions of new interventions.

An important implication of this study for health professionals and policy makers is that they may need to give consideration to the provision of (increased) support to community organisations, which offer activities that are relevant for the self-management of health in people with chronic diseases. Although our study was not designed to provide nationally representative samples, it also suggests that there is room to increase the participation of relevant groups in these organisations. Many diabetes patients reported receiving support from family members, friends and others. The relevance of having a large number of connections was mixed and overall limited, particularly in low-income groups. Therefore, interventions to increase the size of individual support networks need to be applied on the basis of individual assessments rather than taken as the given goals of public health policies.
REFERENCES


### Supplemental table 1. Linear regression estimates (B) for the relation between social support and physical health status per country

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**Social support**

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*p <0.05, ** p <0.01; a Not recorded; b Not included in sampling.

### Supplemental table 2. Linear regression estimates (B) for the relation between social support and mental health status per country

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**Social support**

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*p <0.05, ** p <0.01; a Not recorded; b Not included in sampling.
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* p <0.05, ** p <0.01; * Not recorded; † Not included in sampling.

### Supplemental table 4. Logistic regression estimates (OR) for the relation between social support and healthy diet per country

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<td>1.00</td>
<td>1.29*</td>
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<tr>
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<td>1.90</td>
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* p <0.05, ** p <0.01; * Not recorded; † Not included in sampling.
Supplemental table 5. Logistic regression estimates (OR) for the relation between social support and non-smoking per country

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<thead>
<tr>
<th></th>
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<th>Greece</th>
<th>Netherlands</th>
<th>Norway</th>
<th>Spain</th>
<th>UK</th>
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<td>0.46</td>
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<td>1.04</td>
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<td>1.73</td>
<td>0.84</td>
<td>0.22**</td>
<td>1.53</td>
<td>0.92</td>
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<td>Attending community organisations</td>
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<td>4.87**</td>
<td>1.39</td>
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<td>Urban deprived</td>
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<td>1.16</td>
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</table>

* *p < 0.05, **p < 0.01; a Not recorded; b Not included in sampling.
Chapter 7

Social support and self-management capabilities in diabetes patients: an international observational study

Jan Koetsenruijter
Nathalie Eikelenboom
Jan van Lieshout
Ivo Vassilev
Christos Lionis
Elka Todorova
Mari Carmen Portillo
Christina Foss
Manuel Serrano Gil
Poli Roukova
Agapi Angelaki
Agurtzane Mujika
Ingrid Ruud Knutsen
Anne Rogers
Michel Wensing

ABSTRACT

Objective: The objective of this study was to explore which aspects of social networks are related to self-management capabilities and if these networks have the potential to reduce the adverse health effects of deprivation.

Methods: In a cross-sectional study we recruited type 2 diabetes patients in six European countries. Data on self-management capabilities was gathered through written questionnaires and data on social networks characteristics and social support through subsequent personal/telephone interviews. We used regression modelling to assess the effect of social support and education on self-management capabilities. Results: In total 1,692 respondents completed the questionnaire and the interview. Extensive informational networks, emotional networks, and attendance of community organisations were linked to better self-management capabilities. The association of self-management capabilities with informational support was especially strong in the low education group, whereas the association with emotional support was stronger in the high education group.

Conclusion: Some of the social network characteristics showed a positive relation to self-management capabilities. The effect of informational support was strongest in low education populations and may therefore provide a possibility to reduce the adverse impact of low education on self-management capabilities. Practice implications: Self-management support interventions that take informational support in patients' networks into account may be most effective, especially in deprived populations.
INTRODUCTION

Ageing populations and lifestyle related factors are amongst the factors contributing to an increasing prevalence of many long-term conditions, including type 2 diabetes\(^1,2\). This increase is likely to be higher in groups with a low income and education because they have an increased risk of developing diabetes, as well as of presenting a poorer control of their condition\(^3\). Effective self-management, as part of the chronic care model, can help to improve health outcomes and reduce costs\(^4\). Many educational and counselling interventions have been developed to support behaviour change and to improve self-management of people with long-term conditions. Research on educational and behaviour change programmes for chronic conditions has found varying degrees of success\(^5\). Not only does the effect of these interventions vary, they also have less impact amongst groups with low income and education\(^6\). Many of the available educational and counselling interventions are expected to increase self-management capabilities, such as insight in disease mechanisms, self-monitoring, knowledge, and skills, making use of behaviour change techniques (such as goal setting). This is illustrated by a review that produced an overview of 112 theoretical constructs in behaviour change, resulting in 14 domains of which 12 domains were related to individual traits\(^7\). However, the focus on these individual capabilities may have narrowed the view on what influences self-management and may have missed contextual influences.

When broadening the view to patients’ context, a complementary strategy to contribute to individual self-management capabilities and behaviours is to enhance social support from personal networks and community organisations. Social support is defined as help provided by family, friends, neighbours, or others and includes different domains, such as information, emotional comfort, and practical help\(^8\). Previous studies have shown that social support and social networks influence health behaviours and health outcomes\(^9–13\). This social context may be particularly relevant for people experiencing economic and social deprivation or social isolation, since they have a higher risk of developing diabetes\(^1\). Moreover, self-management interventions maybe less effective for these populations than for those who are more advantaged\(^6\). Support from social networks might provide an opportunity to compensate to an extent for these inequalities in health.

To explain how social networks can impact on health, several mechanisms have been proposed. Network members can provide informational, practical or emotional support. Another mechanism concerns the role of social networks in patients’ navigation to resources (individuals, groups, organisations, and online resources)\(^14,15\). Navigation refers to identifying and connecting with relevant existing resources that are available in a network, such as information and support\(^15\). From the perspective of the individual, access to social support can be characterised as social capital. This social capital can be accessed through weak ties, for example through community organisation or relevant professionals in someone’s wider network. Another
mechanism is contagion: the spread of behaviour, knowledge, and attitudes in populations which is influenced by social networks. This has been suggested to explain the impact of being embedded in a group or population, such as a family, community organisation, or a neighbourhood\textsuperscript{16}. Psychological mechanisms such as imitation of successful behaviours, role modelling, social comparison and exchange of resources may explain the effect of contagion. In addition to social influence from network members, there is also a selection mechanism: networks members are selected on the basis of similarity between a person and potential network members. Both mechanisms (contagion and selection) result in higher homogeneity in networks and create an interaction between composition and content of the network\textsuperscript{17}. In other words, social support networks may influence the content and strength of self-management capabilities, while these capabilities may also influence the support network.

However, insight into the linkages between individual self-management capabilities and support networks in real patient populations is limited. Most previous studies focused on single factors, such as group-based self-management support interventions or self-management interventions with partner involvement\textsuperscript{18,19}. Studies on the simultaneous influence of personal, community organisations and neighbourhood networks seem to be lacking. Therefore, the relative impact of different network characteristics remains unclear. Also, it is unclear whether support networks in deprived patient populations could reduce the adverse effects of a low education.

In this study, we described the personal networks of type 2 diabetes patients and explored which aspects of these networks relate to self-management capabilities, using data from a study in six European countries. Moreover, we explored whether social context factors such as personal networks, community organisations and neighbourhoods can compensate the adverse health effects of a low education by assessing the relationships between self-management capabilities and personal network aspects in high and low education groups.

**METHODS**

**Study design, setting and participants**

An international cross-sectional study in patients with type 2 diabetes was conducted. Data were collected as part of the EU-WISE project\textsuperscript{20}. The study was conducted in 18 purposefully chosen geographical areas in six countries, reflecting a variety of health and welfare systems: Bulgaria, Greece, the Netherlands, Norway, Spain, and the United Kingdom. Within each participating country, one deprived urban area; one relatively affluent urban area; and one deprived rural area (relative to country) was selected. Urban was defined as located in a city with more than 100,000 inhabitants, whereas rural was defined as located in towns or villages with fewer than 30,000 inhabitants. This stratified sampling of areas (rather than a completely random sample in each country) allowed us to study both individual and area characteristics. Because the areas were chosen purposefully, these are not necessarily representative for the countries involved. In each area, 100 patients with a diagnosis of type 2 diabetes were recruited, resulting in about 300 patients in each country. This number allowed us to detect a medium effect size ($f^2 = 0.15$) based
on α = 0.05, intraclass correlation coefficient (ICC) = 0.03, power = 0.80 and the inclusion of eight independent variables in the analysis\textsuperscript{20,21}. Patients attending primary or ambulatory healthcare practices in the defined geographic areas were recruited. This method of recruiting has the advantage of a confirmed diagnosis of diabetes by a physician and provides the possibility of a face-to-face contact with the patient. This personal contact can enhance participation, but inhibited the calculation of a meaningful response rate. Inclusion criteria were: medical diagnosis of type 2 diabetes and aged 18 years or over. Exclusion criteria were: pregnancy; pregnancy-related diabetes; recent/current major surgery or medical procedures; severe cognitive or psychiatric handicap; terminal illness/receiving palliative care; absence of translators (e.g. family members) for patients with insufficient language skills. Eligible patients were given an invitation letter with information, a consent form, and a written questionnaire via their healthcare practice. Participating patients were invited to take part in an interview as well. Ethical committees in the participating countries provided approval for the study.

**Measures**

Data collection consisted of two parts: the first part was a written questionnaire with validated measures recording demo-graphic variables, co morbidities (high blood pressure, high cholesterol, angina pectoris, heart attack, coronary surgery, heart failure, transient ischaemic attack, stroke, peripheral arterial disease), participation in local organisations and self-management capabilities; the second part was a pre-structured face-to-face or telephone interview, focussing on social networks and social support. We chose for interviews for the social network questions, based on pilot testing in 25 diabetes patients, suggesting that written surveys of these measures were not feasible in the targeted population.

**Social support measures: individual support networks and community organisations**

Data on the number of household members, presence of spouses and participation in community organisations were gathered using structured questions. Participating in community organisations was defined as visiting a community group, activity or service from a community group at least once a month within the last 6 months. Data on individual support networks was collected through interviews using a validated name generator method in which participants were asked to generate a list of persons that were valuable to them\textsuperscript{22}. This method first requires a respondent to name actual persons and then several additional questions about these individuals are asked. For each individual mentioned through the name generator additional data was derived such as age, gender, type of relationship with the respondent, and whether a member provided informational, practical or emotional support. Informational support was defined as exchanging information related to dealing with someone’s illness; practical support as providing help with practical things in and around the house; emotional support was defined as talking about health problems or other personal issues\textsuperscript{8}. Network members were divided into three types: family members, non-family members (friends, neighbours), and healthcare
professionals. Finally, the position generator was used to identify access to specified professionals (nurse, doctor or pharmacist). This method measures access to network members' occupation that functions as a source for social capital. Unlike the patient’s self-reported support network, which only included close members, the professionals identified through the position generator could be part of patient’s wider environment.

**Individual demographic measures**

In this study we used education as a proxy for SES, because self-management capabilities are often linked to educational interventions. Low education was defined as an education up to secondary school, whereas college and university were defined as high education. Besides education, income, origin of the parents, and a short list of nine comorbidities were measured. We measured income relative to the country’s average income. Respondents answered whether their income was below/about/above the country yearly average income (BG 4500 lev; GR 12,000 EUR; NL 33,000 EUR; NO 350,000 Nkr; ES 22,800 EUR; UK 25,000 pound). Low income was defined as income below the country yearly average income for each country.

**Self-management capabilities**

In this paper we focused on the necessary capabilities to manage illness related symptoms successfully. To measure these capabilities, we used two domains of the validated Health education impact questionnaire (HeiQ). The domain 'self-monitoring and insight' (SMI) captures the individual’s perceived ability to monitor the condition, and the ability to reflect on how self-management actions influence the physical and emotional status. High scores indicate a good self-monitoring, self-management, setting reasonable limits or targets, and insight into living with a health problem. This scale consists of 6 items, such as 'With my health in mind, I have realistic expectations of what I can and cannot do' and 'I know what things can trigger my health problems and make them worse'. The domain 'skill and technique acquisition' (STA) consists of 4 items on knowledge-based skills and techniques that are important for patients to manage their condition. High scores are characteristic of someone who has highly developed skills in symptom relief and techniques to manage own health. Examples of items in this domain are: 'When I have symptoms, I have skills that help me cope' and 'I have a very good idea of how to manage my health problems'. Scores on all items could vary from 1 (strongly disagree) to 4 (strongly agree) and both scales (SMI and STA) were calculated as the mean of the individual items and therefore ranged from 1 (min) to 4 (max).

Measures that were not yet available in all countries were translated into the specific language using forward- and back-translation, and were culturally adapted to the specific country characteristics. In Bulgaria, two researchers independently translated the HeiQ and RAPA into the Bulgarian language. Consensus on both translations was done by a third researcher and the final version of the translated questionnaire was translated back by a professional translator. For the
HeiQ, an extensive discussion on the translation with the developer of the HeiQ (Richard Osborn, Deakin University) was also included, so that they received an official licence for use in Bulgaria. In Greece, the RAPA was translated by three researchers and a professional translator independently. After reaching consensus, back translation was done by the same team and cultural adaptations were made. The newly translated questionnaire was pilot tested in three diabetes type 2 patients in order to test clarity and understanding.

Statistical analysis
To determine the effect of social support on self-management capabilities, we performed a regression analysis with self-management capabilities as dependent variables and social support characteristics as independent variables. Both the HeiQ scales were treated as interval scale and therefore analysed using ordinary least squares (OLS) regression model. The regression analyses were based on a multilevel model with a random intercept with patients nested both within areas and in the six participating countries²⁶.

We first analysed the whole sample, taking level of education into account. Secondly, we explored whether social support has the same effect on self-management capabilities in high and low education groups. Countries and areas were not randomly sampled, and therefore, generalisation beyond chosen areas and countries was avoided. In all analyses, we controlled for patients’ age, gender, comorbidity, parents born in other countries, and income as potential confounders. Significance was indicated by p < 0.05 and analyses were performed using IBM SPSS statistics 20 (IBM Corp.).

RESULTS
In total 1,861 patients completed the written questionnaire, of which 1,692 participated in the interview. The average age was 66.1 years, ranging from 59.8 in Norway to 69.3 in Spain. Men and women were equally present (50.0% female), but ranged from 38.5% female in Norway up to 61.1% in Bulgaria. Overall, 6.0% had a parent that was born abroad, mostly in the Netherlands (13.9%) and Norway (14.4%). The majority had a low income relative to country average (61.0%; range 46.2% in Norway, 81.1% in Spain) and low education (61.5%; range 38.7% in Bulgaria, 90.6% in Spain), reflecting the focus of the study on deprived populations. Participants reported an average of 3.2 connections (median 3) with individuals providing some kind of support. Respondents in Greece reported the least connections (2.2), respondents in the Netherlands and UK most (4.1). Emotional support was the most prevalent form of support with an average of 2.5 network members, followed by 1.9 for information support and 1.5 for practical support. Information support shows the largest difference between countries from only 0.9 in Greece up to 2.8 supportive members in the UK. Nearly half (48.3%) had healthcare professionals in their extended network which varied from 31.4% in Spain up to 57.6% in Greece. About a third (34.6%)
participated in community organisations, mostly in the Netherlands (44.1%) and the least in Norway (23.7%) (Table 1).

Table 1. Description of patient samples

<table>
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<tr>
<th></th>
<th>Total</th>
<th>Bulgaria</th>
<th>Greece</th>
<th>Netherlands</th>
<th>Norway</th>
<th>Spain</th>
<th>UK</th>
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<td></td>
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<td>(n=283)</td>
<td>(n=302)</td>
<td>(n=245)</td>
<td>(n=291)</td>
<td>(n=290)</td>
<td>(n=281)</td>
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<td>65.2</td>
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<td>69.3</td>
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<td>75.3</td>
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<td>69.3</td>
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<td>47.5</td>
<td>46.2</td>
<td>81.1</td>
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<td>62.4</td>
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<td>90.6</td>
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<td>60.6</td>
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<td>59.7</td>
<td>59.4</td>
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<td>Spouse (% yes)</td>
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<td>62.1</td>
<td>70.9</td>
<td>74.7</td>
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<td>81.2</td>
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<td>2.2</td>
<td>4.1</td>
<td>3.3</td>
<td>3.0</td>
<td>4.1</td>
</tr>
<tr>
<td>Network members providing:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Information support</td>
<td>1.9</td>
<td>1.9</td>
<td>0.9</td>
<td>1.6</td>
<td>1.9</td>
<td>2.2</td>
<td>2.8</td>
</tr>
<tr>
<td>Practical support</td>
<td>1.5</td>
<td>1.8</td>
<td>1.2</td>
<td>1.2</td>
<td>1.2</td>
<td>1.6</td>
<td>1.8</td>
</tr>
<tr>
<td>Emotional support</td>
<td>2.5</td>
<td>2.7</td>
<td>2.1</td>
<td>2.5</td>
<td>2.6</td>
<td>2.6</td>
<td>2.8</td>
</tr>
<tr>
<td>Network members type:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family members</td>
<td>2.0</td>
<td>1.7</td>
<td>2.1</td>
<td>2.3</td>
<td>1.7</td>
<td>1.8</td>
<td>2.2</td>
</tr>
<tr>
<td>Nonfamily members</td>
<td>0.5</td>
<td>0.5</td>
<td>0.1</td>
<td>0.6</td>
<td>0.8</td>
<td>0.2</td>
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<tr>
<td>Healthcare professionals</td>
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<td>1.2</td>
<td>0.8</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Healthcare professional in wider network (% yes)</td>
<td>48.3</td>
<td>54.8</td>
<td>57.6</td>
<td>47.8</td>
<td>49.8</td>
<td>31.4</td>
<td>48.0</td>
</tr>
<tr>
<td>Participating in community organisations (%)</td>
<td>34.6</td>
<td>37.8</td>
<td>24.8</td>
<td>44.1</td>
<td>23.7</td>
<td>41.4</td>
<td>38.1</td>
</tr>
<tr>
<td>Residential area</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban deprived</td>
<td>35.9</td>
<td>35.3</td>
<td>32.8</td>
<td>37.6</td>
<td>35.4</td>
<td>33.1</td>
<td>42.3</td>
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<tr>
<td>Urban affluent</td>
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<td>32.2</td>
<td>32.8</td>
<td>21.6</td>
<td>30.6</td>
<td>32.8</td>
<td>57.7</td>
</tr>
<tr>
<td>Rural deprived</td>
<td>25.0</td>
<td>32.5</td>
<td>34.4</td>
<td>40.8</td>
<td>34.0</td>
<td>34.1</td>
<td>- b</td>
</tr>
<tr>
<td><strong>Self-management capabilities</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self monitoring and insight</td>
<td>3.11</td>
<td>2.98</td>
<td>2.98</td>
<td>3.11</td>
<td>3.25</td>
<td>3.11</td>
<td>3.22</td>
</tr>
<tr>
<td>Skill and technique acquisition</td>
<td>2.89</td>
<td>2.74</td>
<td>2.77</td>
<td>2.98</td>
<td>3.06</td>
<td>2.81</td>
<td>3.00</td>
</tr>
</tbody>
</table>

a Not recorded; b Not included in sampling.

Table 2 presents the results of the analyses with the association between individual and social network characteristics and self-management capabilities. Low education (beta = -0.11; p < 0.01) and more practical support members (beta = -0.06; p = 0.04) were associated with lower SMI. More network members providing information support (beta = 0.09; p < 0.01) or emotional support beta (beta = 0.11; p < 0.01), and participation in community organisations (beta = 0.06;
p = 0.03) were associated with higher SMI. The association with the number of network members who provided information support was especially strong in the low education group (beta = 0.13; p < 0.01 vs beta = 0.05; p = 0.29), whereas the association with the number of emotion support network members seems stronger in the higher education group (beta = 0.18; p < 0.01 vs beta = 0.07; p = 0.21). Low education (beta = -0.10; p < 0.01) and low income (beta = -0.09; p < 0.01) were both associated with lower STA. Regarding the social network factors, only the number of network members providing information support was related to higher STA (beta = 0.09; p < 0.01), especially for low income populations (beta = 0.11 p < 0.01 vs beta = 0.05 p = 0.23). Within the low education group, having a healthcare professional in someone’s wider network was associated with higher STA (beta = 0.07; p = 0.04). For the high income group, having a spouse was related to higher STA (beta = 0.12; p < 0.01), whereas the number of household members was associated with lower STA (beta = -0.11; p = 0.02). The proportion explained variance (adjusted R square) by this model was 0.061 for 'self-monitoring and insight' and 0.067 for 'skill and technique acquisition'.

Table 2. Linear standardised regression estimates (beta) for the relation between social support and self-management capabilities

<table>
<thead>
<tr>
<th></th>
<th>Self monitoring and insight</th>
<th>Skill and technique acquisition</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Overall multi-variate</td>
<td>Low education group</td>
</tr>
<tr>
<td></td>
<td>Low education group</td>
<td>High education group</td>
</tr>
<tr>
<td>Age (10 year steps)</td>
<td>-0.01</td>
<td>-0.03</td>
</tr>
<tr>
<td>Sex (male ref.)</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Low income</td>
<td>-0.04</td>
<td>-0.04</td>
</tr>
<tr>
<td>Parents born in other country</td>
<td>-0.04</td>
<td>-0.01</td>
</tr>
<tr>
<td>No comorbidities (ref.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2 Comorbidities</td>
<td>-0.07*</td>
<td>-0.06</td>
</tr>
<tr>
<td>&gt; 2 Comorbidities</td>
<td>-0.04</td>
<td>-0.02</td>
</tr>
<tr>
<td>Low education</td>
<td>-0.11**</td>
<td></td>
</tr>
<tr>
<td>Social network characteristics</td>
<td></td>
<td></td>
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<tr>
<td>Spouse</td>
<td>0.03</td>
<td>0.00</td>
</tr>
<tr>
<td>Household members</td>
<td>0.00</td>
<td>0.01</td>
</tr>
<tr>
<td>Network members providing:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information support</td>
<td>0.09**</td>
<td>0.13**</td>
</tr>
<tr>
<td>Practical support</td>
<td>-0.06*</td>
<td>-0.09*</td>
</tr>
<tr>
<td>Emotional support</td>
<td>0.11**</td>
<td>0.07</td>
</tr>
<tr>
<td>Number of family members</td>
<td>-0.06</td>
<td>0.00</td>
</tr>
<tr>
<td>Number of nonfamily members</td>
<td>-0.02</td>
<td>-0.02</td>
</tr>
<tr>
<td>Health professional in wider network</td>
<td>0.04</td>
<td>0.05</td>
</tr>
<tr>
<td>Participating in community organisations</td>
<td>0.06*</td>
<td>0.05</td>
</tr>
<tr>
<td>Neighbourhood (urban affluent = ref.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban deprived</td>
<td>0.02</td>
<td>0.03</td>
</tr>
<tr>
<td>Rural deprived</td>
<td>0.05</td>
<td>0.02</td>
</tr>
<tr>
<td>Adjusted R-square</td>
<td>0.061</td>
<td>0.034</td>
</tr>
</tbody>
</table>

* p<0.05,  ** p<0.01
DISCUSSION AND CONCLUSION

Discussion

Our findings are partly consistent with other studies that focus on the influence of social support and social networks. The mixed effect of individual support networks was also found in a systematic review reporting tentative evidence for social support\textsuperscript{27}. The finding that a large information network is beneficial for self-management capabilities, especially in low education populations, provides additional information about the influence of networks\textsuperscript{28,29}. We found that resources available in a network can influence individual capabilities, but that this relationship is not necessary equally strong for all type of networks. For example, a more extensive informational support network may mean that individuals have access to different types of information, which is not available from one person only, and can compare these sources of information. This seems more relevant for people with a lower education whose network, due to homogeneity tendencies, might include less accurate information if this is provided by only one network member\textsuperscript{17}. Although previous research found different effects for support provided by family or provided by non-family members, we did not find a significant difference between these types of network members\textsuperscript{30,31}. Therefore, we conclude that it is more important how many network members provide informational or emotional support than if this person is a family member or not.

A strong aspect of this study is that the involved countries reflect a variety of health and welfare systems and policies in response to austerity in Europe. This enhances the robustness and generalisability of the findings. The focus on areas made it possible to combine various types of social support (from individual networks, community organisations, and neighbourhoods) in one analysis. While we used previously validated measures and methods, the study has a risk of bias due to non-identified differences in national health systems and cultures. Also, the cross-sectional design of the study did not allow causal inferences, so we could only speculate about mechanisms underlying the effect of social support. This is most prominent in the relationship between self-management capabilities and network composition. While self-management capabilities are shaped by the composition of someone’s network, personal traits, related to self-management capabilities, might also influence the composition of the network. Therefore, there is a mutual relationship between these two factors which is hard to distinguish. To study the causality, a longitudinal study would be necessary.

Conclusion

Education and income were negatively related to self-management capabilities, but larger informational and emotional support networks showed a positive association with self-management capabilities. The relative influence of social network characteristics was just as important as individual characteristics, but the total variance explained was low. Most obvious was that more network members providing information was consistently related to better self-
management capabilities. This link was especially strong within the low education group, suggesting that people with a low education may benefit most from a large information network. Thus, this study provides evidence that strong social support may compensate for the adverse impact of low education, at least with respect to self-management capabilities of diabetes patients.

**Practice implications**
Although the overall variance in self-management capabilities explained by the regression model was small, some guidance to strengthen self-management support interventions can be provided. Enlarging the number of network members providing information support can compensate for the adverse effects of deprivation. Therefore, interventions should not only focus on the individual patient, but also involve his/her social network to maximise this effect, especially in low education groups. This supports the involvement of patients' partners and groups in self-management support interventions\(^{18,19}\). However, how and whether such an intervention is effective should be tested in further research using a RCT design. Furthermore, the positive effect of participation in community organisations reflects the supportive function for self-management in people with chronic diseases. Policy makers may need to give consideration to providing (increased) support to community organisations, to strengthen this function.
REFERENCES


Chapter 8

From social networks to social support: what does it take for diabetes patients to create supportive networks?

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Ivaylo Vassilev
Jan van Lieshout
Anne Rogers,
Anne Kennedy
Michel Wensing

Submitted.
ABSTRACT

Introduction: The social environment plays an important role in how patients with type 2 diabetes deal with their disease. Structural and functional sociological theories can explain how support is generated. The aim of the study was to explore through empirical testing which theory-based mechanisms are relevant to type 2 diabetes patients in generating social support network.

Methods: A qualitative study using semi-structured interviewing was conducted within 25 type 2 diabetes patients in The Netherlands. The interviews used a biographical approach and covered topics about the social support received. Data were analysed using a framework method.

Results: Identifying and selecting network members was a relatively unreflexive process because a network was considered given and not within their control. Negotiating support was often mentioned and perceived to be guided by social norms. Social comparison was relevant to create social engagement related to family members and community organisations.

Discussion: Factors related to negotiation and contagion were prominent in the perceptions of deprived diabetes patients. Embedding in a (community) organisation may provide valued feelings of engagement. Considering the relevance of reciprocal relationships identified in narrative accounts, the design of future interventions may usefully focus on what kind of support patients can provide to others.
INTRODUCTION

The prevalence of long-term conditions is increasing globally. This poses a challenge for governments to provide accessible, high-quality healthcare for reasonable costs. Enhancing self-management capabilities of individuals through educational and counselling interventions is one way to deal with these developments. Increasing individual competencies through self-monitoring and making use of behaviour change techniques can help to improve health outcomes. In addition to improving individual competencies, an increasing body of research focuses on harnessing social support from personal networks as a mean to enhance self-management behaviours and health outcomes. Studies have shown that social support and social networks can influence both health-related behaviours and a range of health outcomes, including mortality. For patients with long-term conditions, the social environment can even be more important because this is the setting where they have to manage their disease most of the time. Effects of social networks on health related outcomes have indeed been shown to influence outcomes in patients with long-term conditions. In this study we focus on factors and mechanisms underlying the impact of social networks on social support.

Different pathways have been proposed in how networks might influence health status e.g. social support, social influence, social engagement, and access to material resources. These pathways have their origin in different theoretical and methodological origins.

From a structural networks perspective, advanced statistical models have been developed to evaluate network dynamics and to predict changes in the structure of networks. This actor-centric theoretical perspective, which utilizes rational choice theory and has its roots in social psychology and sociology, describes how social networks are created. Although this structural approach can demonstrate how the layout of networks is formed, and the co-evolution of structures and behaviours, it is not developed to predict how networks have an impact on health outcomes. From a functional perspective, constructivistic theories have been developed informing on how social networks can contribute to health outcomes. Social capital, the idea that social networks create value to an individual, is an important mechanism in this process. In addition to identifying what social networks mean for people, the question how networks ties are created and recreated is relevant to understanding the generation of social capital. Contrary to theories with a structural perspective these mechanisms are not based on rational choice theory, but rely on theory concerning socio-psychological capacities necessary to create and maintain social relationships. This approach considers changes in the structure of a network, as well as how people generate more (or less) support in their existing network. In a metasynthesis of qualitative studies on social support networks for diabetes patients, three different network related mechanisms linking to health outcomes were specified; navigation, negotiation and collective efficacy. These mechanisms capture the network dynamics which are responsible for the creation of a strong support network.
Both structural and functional theory is important to understand how supportive networks for type 2 diabetes patients are established. However, few studies have integrated both theories in the analysis, so that the relation between and relative importance of each of the approaches is unclear. In this paper we combine these two theoretical approaches to investigate if and how the involved mechanisms apply to our setting.

**Structure of networks: Social selection and social influence**

From structural network theory, we have deduced two important mechanisms for the impact of support networks: social selection and social influence. Social selection is the process in which new network ties are created and describes how ties between people are formed and dissolved, based on certain criteria, often homophily or similarity of individuals\(^{16}\). With whom network ties are created may depend on factors such as possible candidates, opportunities to connect, and the similarity between ego and potential relational partners. This latter is the idea of homophily which is *"the principle that a contact between similar people occurs at a higher rate than among dissimilar people. Homophily structures network ties of every type, including marriage, friendship, work, advice, support, information transfer, exchange, co membership, and other types of relationship"*\(^{17}\).

Social influence is based on the assumption that people who are connected tend to influence one another\(^{18}\). This idea has further been developed by the notion of contagion. Contagion explains how attitudes and behaviour spread through social networks, as if they were infectious diseases. Which specific mechanisms are responsible for the contagion of network members is not always clear, but these could include mechanisms such as social comparison and role modelling. It has been shown that contagion seems to apply to a range of items, including the spread of happiness, health-related behaviours, diseases and risk factors (e.g. smoking, obesity, and depression)\(^ {9,22}\). Both social influence and social selection enhance homophily between connected people. However, the question which of these two mechanisms is more important for this similarity between actors is under debate and may depend on the context\(^ {19}\). Social influence and social selection are important constructs to explain and potentially predict how networks evolve during time. Therefore, the structural layout of a network is important for the potential of support that is available in a network.

**Functioning of networks: Navigation, negotiation and social engagement**

When reflecting on the functioning of networks, three network related mechanisms were distinguished: navigation, negotiation and social engagement\(^ {15}\). These mechanisms were tested in a qualitative study and further developed by exploring more themes\(^ {20}\). Navigation builds on pre-existing relationships and involves how people identify and connect with relevant potential resources in a network. More specifically it involves making decisions about who to contact when support is necessary and to identify if there are potential unused resources in a network. Successful navigation can improve the access to relevant resources and information within a
network. Therefore, understanding how patients navigate can help to make support for patients more easily accessible. Negotiating involves dealing with roles, expectations, and communication between network members. This is important when patients need support from their network and relationships between network members change. Questions arise about what they can still do themselves and who they can and cannot ask for support. Considering our sample of diabetes patients, negotiating especially deals with the question of how support is made available to the individual.

Social engagement (also labelled as collective efficacy or connectiveness) refers to ‘developing a shared perception and capacity aimed at successful management’ \(^{20}\). Within a network collective efficacy could stimulate healthy practices by creating shared efforts and objectives which support a patient’s ability to adhere to a self-management regimen. It also includes the positive identity that individuals can derive from being part of a group, such as a family, neighbourhood or sports team.

The network mechanisms, which are specified in the two theoretical approaches, can be organised by the aggregation level in which they operate. Some mechanisms are related to how individual actions shape a network, other mechanisms are related to how a network can influence individual behaviour. This combination of the level at which network mechanisms operate and the theories that reflect on networks can be brought together in a matrix (Figure 1). The distinction between the categories in this matrix is not always a clear line, but it is considered a heuristic tool to organise the framing of the analysis.

**Figure 1. Matrix of network theories and level of operation**

<table>
<thead>
<tr>
<th>Level of operation</th>
<th>Network theories</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Structure of networks</td>
</tr>
<tr>
<td>Individual actions influencing the network</td>
<td>Selecting relations</td>
</tr>
<tr>
<td>Network influences on the individual</td>
<td>Social influence (contagion)</td>
</tr>
</tbody>
</table>

Looking at the structure of networks, individual actions on the network can influence a network through the selection of network members. Network influences on the individual work through social influences mechanisms, also known as contagion mechanisms. When we look at the functioning of networks, individual actions on the network are related to how people seek access to sources of support. Relevant mechanisms are navigation (using existing ties to find sources of support) and negotiation (dealing with roles, expectations, and communication between network members to make support available to the individual). The network influences the individual through the mechanism of social engagement (creation of collective responsibility and sense of belonging).
The aim of the present study was to explore whether these theory-based mechanisms are relevant to type 2 diabetes patients in how they generate a strong social support network. More specifically, we explored how diabetes patients reflect on the potential of social networks for their health and how they can potentially use social networks for their own benefit.

**METHODS**

A qualitative interview study was conducted to meet the aims of the study. By using a qualitative design, we were able to detect the variety in which networks mechanisms work. The design and report of the study was guided by the COREQ guidelines, a 32-item checklist designed to help researchers to report important aspects of the research team, study methods, context of the study, findings, analysis and interpretations\(^2\). Data were collected as part of the EU-WISE project, an international project in six European countries. This study is based on the interviews held in The Netherlands. Interviews were held between May 2012 and November 2013 in a deprived area in a midsized city in The Netherlands. In the sampling of participants, we aimed to maximise the diversity of the sample in terms of gender, age, ethnicity and level of isolation. The level of isolation was defined by the GP’s indication of the size of a participant’s social network. The GP generally is aware of this information, being used to take contextual factors in account. Deprivation of the area was indicated by a relatively high percentage of households with low household income. Most participants were selected by a general practitioner who was also part of the research team. In addition, some participants were selected through a local elderly organisation to ensure a certain level of socially active respondents. Respondents selected by the GP were invited face-to-face, respondents selected by the elderly organisation were invited by e-mail. Recruitment and interviews with participants took place in multiple steps and in between interim analyses were done to enhance relevant diversity in the sample. In total, 25 respondents were interviewed until our sample captured the whole diversity in type of respondents.

**Setting**

All interviews took place at the respondents' home. In most interviews, only the respondent was present, in some interviews a close relative was also present. Twenty respondents were aged over 60 years of whom 7 over 75 years. Females were slightly overrepresented with 14 out of 25 and 12 respondents still lived with a partner whereas 13 lived alone for different reasons (mostly widowed). Ethnic minorities were represented by 5 non-western respondents (Turkish, Moroccan, and Surinamese).

**Data collection**

The interviews were semi-structured with in the first part some open questions that used a biographical approach and where the intention was to talk freely. The topic was how they experienced being diagnosed with diabetes, how their lives were changed by this, and what others were involved in this process. The second part included more specific questions about
responsibility for health, style of coping and resources of support. The third part focussed upon aspects of the respondent's network and made use of a circle diagram on a sheet. This circle diagram consisted of three concentric circles and with the respondent in the middle. Respondents were asked to indicate how close to the middle a specific network member should be entered. This way, the circle diagram was used to discuss and map the support that was available in the respondents' networks. The interview guide was tested in 5 pilot interviews and some adjustments were made afterwards. During the other interviews some questions were added and some removed based on interim analysis. All interviews were conducted face to face, were recorded and verbatim transcribed. After each interview, short field notes were made by the interviewer. The interviews lasted between 40 minutes and 80 minutes.

Framework for analysis
For the analysis in this article we used the Framework Method\textsuperscript{22}. This method uses a pre-existing theory but allows for unexpected findings, thus allowing both a deductive and inductive approach. The use of a matrix keeps the views of each respondent connected and therefore comparisons within and between cases are possible. The framework method uses 7 stages; transcription, familiarisation with the interview, coding, developing a working analytical framework, applying the analytical framework, charting data into the framework matrix, and interpreting the data. At stage 1, transcription was done as part of the data collection. Familiarisation was achieved by reading and discussing the interviews with the research team. Coding was done by two members of the research team independently following a deductive approach. However, we allowed for some open coding to ensure that we did not miss important aspects of the data. After coding of every few interviews, the research team compared the labels they applied to the transcripts to reach consensus and these labels were entered in the predefined analytical framework. The working analytical framework was then applied by indexing the transcripts and the quotes related to the labels were entered into the framework matrix. Finally, the characteristics of the data were explored and interpreted to test how it fitted within our predefined framework and what new themes emerged. This again was an iterative process where new ideas and typologies were generated and discussed.

RESULTS

Individual actions influencing the network

Structure of networks: selecting relations
Looking at how individual actions can influence the network structure, we found that the selection mechanism was clearly apparent in the biographical interviews. Most of the respondents mentioned selection related topics. Within this process of selecting relations, we found two subthemes that capture the difference between starting and dissolving relationships. Starting relationships concerns how respondents reflected on the forming of relationships. Not
many respondents mentioned specific reasons why someone was part of their network. When they mentioned something, this consideration about forming relationships was mostly based on finding similar others, for example other patients with the same illness or people from the same age. If a neighbourhood has few people with similar characteristics, patients found it harder to form new relationships.

"Yes, they also play games there. And there are fellow sufferers, they are important in everything you do."

Besides choosing to start a relationship, respondents also reported that they sometimes dissolve an existing relationship with a specific person or group. A specific issue in our sample with type 2 diabetes patients was that they are relatively old and therefore network members pass away, however if they choose to dissolve a relationship this often had to do with relational issues within a family.

"But I am not in contact with my family anymore." (...) "At least, my children don't want me to contact that part of the family. They insulted my children too much for that."

Overall our respondents gave a variety of reasons why they started or dissolved relations. However, these reasons were more a kind of justifying rather than an indication that they can influence these processes of creating networks by themselves. They had the feeling that there were good reasons for how their network looked like, but they had few reflections on their own influence in this process.

Functioning of networks: navigation
Looking at how networks can function, we found few reflections on how patients navigate to potential resources of support within their network. In one case a phone number of a relevant connection was offered by a neighbour. Interestingly, most indications of navigating were found in how people used the internet. Navigation may not be very common within a network, but broadened to the internet as a means to find resources such as information and community groups, navigating was quite common.

"The only thing I use internet for is to search for topics I would like to know something about, or websites that I read about and think, hey, that can be interesting. Not for other things, no. I have some kind of medicine seeker, so I can see what the medicines are that I use."
Functioning of networks: negotiation

Nearly every respondent mentioned issues that are related to the concept of negotiating. Our respondents struggled with issues as: 'can I still do this task myself?, and if not, is it all right to ask others for support?'. And even more: 'what can I do in return?' We found two types of considerations that guided the decisions in this process: social norms and reciprocity.

Expectations, roles, and norms about social relationships were important to patients to decide who they ask for support. A common issue was that respondents did have relationships beyond family boundaries, such as acquaintances and neighbours, but they were not allowed to become very close. This especially applied to health issues that were considered very personal. Within close family ties all family members were usually involved, but friends, neighbours and acquaintances were not supposed to become too close to them and were often not involved in the support network.

"Well, your family and the grandchildren. And we have some good friends that are important to us, but we never discuss this, that I have diabetes. They all know it, but we never talk about it."

Respondents had different reflections on why they did not involve a broader range of relationships. Some patients did not consider themselves very ill and therefore experienced no need to bother others with their disease. Others considered their illness their own issue and not something they should bother others with. A very common reply was 'well, I have to do it myself, haven't I?' Some respondents had the feeling that others did not understand what their disease meant to them and therefore they did not even bother trying to involve them.

"It is me who has diabetes, not her. I shouldn't bother others with it. And it is just me who has it. I am not going to start an emotional discussion about how it feels to have diabetes and what do you think about it. No, that's not how we are."

An important finding was that although all respondents were diabetes patients, this did not hinder them in providing support to others in their network. For example, watching their grandchildren or providing emotional support to friends that had a hospital visit. This means that diabetes patients not only receive support, but also provide forms of support. This pattern of a mutual exchange refers to the concept of reciprocity which means that a balance arises between receiving and providing services and was important in many of the considerations about dealing with social relationships. For example, a specific issue was that due to the fact that our sample consisted of diabetes patients, most people might need more support than they can give. And when an imbalance occurred between receiving and providing support, the norm of reciprocity was not met, which made people feel uncomfortable.
"Yes, yes, it is very annoying when you become disabled and you are not able to do certain things anymore. When in September the husband of my friend passed away and I was not able to attend the wake or to support her... Yes, that hurt me a lot, because otherwise I would have done that."

When respondents experienced a clear 'violation' between the amount of support they provided and received, this could even be a reason to dissolve a relation. This happened when people had the feeling that they had to provide too much support without getting something in return. This imbalance could occur in all dimensions, varying from providing emotional support to more elementary kinds of support:

"Yes, she has medicines for those voices in her head. But still she is bothering me with those voices. That is something I don't want either, I got crazy too. When she was at the hospital she called three times! I told her to call her brother or sister, because you get mad when she bothers you every time with those voices. (...) Sometimes I don't even answer the phone when she calls me, she only has my mobile phone number. If I gave her my home phone number she would call me all day and I don't want that."

Network influences on the individual

Structure of networks: social influence

Although social influence may be a concept that goes beyond the influence and consciousness of individual network members, about half of the respondents reported some reflections that cover this concept well. A reflection often encountered was based on social comparison; in reflecting on their own behaviour, respondents often tended to refer to other people in their environment that show a particular behaviour. This person could be a role model, but more often it was someone who showed a particular behaviour that they found was inappropriate and therefore an example of how they did not want to be. This form of social comparison could provide a motivation to keep to their regimen. As one respondent put it:

"Yes, it went so fast... That's why I was pretty scared. I thought, I don't want to become like my mother in law... You see, that's it."

An interesting finding was that social comparison with family members could result in worse self-management. When other family members also have diabetes, they experienced their own disease as something genetic and beyond their own influence. This could potentially make them less motivated to do their best managing their disease.
"I had several operations and they never diagnosed diabetes, I never expected that I had diabetes. But it runs in the family, you see. Diabetes... And cancer too, they have colorectal cancer too. That’s it. It all appears in our family."

Besides social comparison, only a very direct effect of social influence was reported when network members stimulated the respondent to perform a particular behaviour. This stimulation was often given by a close relative and concerned for example exercising together. However this can be seen as social influence, it also links to the notion of social engagement and will be addressed there too.

**Functioning of networks: social engagement**

Social engagement was mentioned by almost all respondents and mainly found within family relationships and community organisations. Within families, often a shared goal (control diabetes) existed, which motivated the other family members to support an ill family member. Respondents reported very functional types of support within a family, such as cooking healthier meals and exercising together. In these cases, a 'collective' change of practices takes place; based on a shared goal and together with other personal community members e.g. ones partner.

"My wife becomes 65 years old this year, so you are going to live a different life. You are together and you are going to eat less and do more healthy things. Cycling and that kind of stuff. It is a different approach in your life."

Besides this functional type of support, there is also a more engagement related dimension. This engagement was illustrated by respondents when they described how family or members from other groups were concerned with their wellbeing and health.

"Yes, they always call me when I have been to the medical specialist. Because my wife tells them. I am not going to tell them that I am going to the specialist, but those women, but they call each other more often. And then they chitchat and so on, and well, then they know about it. They ask when I have to go and then they call me when I am back home. So yes, there is concern and we are concerned about others as well, yes. It is not excessive; we are really just a boring family."

A specific function of social engagement within groups was that it offered a 'platform' to exchange the provision of support within a group. When respondents were part of a group, the exchange of support happened more naturally. This was common within families where, for example, grandparents look after their grandchildren and the children provide practical and emotional support when necessary. But also other kind of groups provided such a platform, even when it was only a loose membership base, such as sharing the same building.
I: "Who else is important to you?"
R: "The neighbours. We are both, me and two women, in the resident committee of this building. They drop by now and then and on other moments I visit them."

Being embedded within a community organisation provided respondents also direct benefits. These organisations provided a place for interactions between people, but also provided specific services such as activities, information and practical support.

"I am also member of the diabetes fund. Some time ago I was collecting money and then they keep you up to date about developments around food or anything else that is new. I enjoy it to collect all this information. And you see, I use this information to carry on."

Although the feeling of being embedded was important for many people, not everyone is looking for this kind of commitment. Especially when it comes to join a community group, many people suggested different reasons why they were not this kind of person to join a group.

"No, I used to do that, being member of a club and so on. But then they want you to come mandatory and then it is over for me."

DISCUSSION
Main findings
This study showed that both the structural and functional theories are relevant to describe and explain how networks operate in diabetes patients, although we found also pieces of overlap. Focussing on one theory would not present a complete picture of the complexity of support networks for diabetes patients. The structural approach mainly provided an understanding in how relationships were formed and dissolved and revealed that the establishment of a support network is often not considered a process that is within the control of patients. It also highlighted how the process of social comparison can explain both negative and positive effects of social contagion. Looking from a functional approach, we found what kind of efforts a patient needed to do in order to generate support from their network. Especially the frequent appearance of negotiation showed that type 2 diabetes patients have a lot of social aspects that they have to deal with to create and sustain a supportive network. The finding that people had the feeling that having diabetes is something that they have to deal with alone restricts the possibilities to generate support from a network. The limited capacity to reciprocate support due to poor physical capabilities puts a further restriction on the potential for support.
Embedding in literature

Our findings illustrate that social processes play an important role in the process of self-management for people with type 2 diabetes. This importance of the social environment corresponds with recent findings that the setting in which the diabetic patient lives was an important reason why patients with diabetes might fail to maintain good diabetic control. The struggle to create and sustain a supportive network illustrated the need for ties that are easier to maintain, such weak ties and community based organisations. This corresponds with findings that weak ties have a potential in supporting long-term condition management and that participation in community organisations was associated with more physical activity for patients with low income. Furthermore, a review suggested that education also should be provided for those who directly influence the patients’ lifestyle in order to avoid potential tension, which reflects the efforts that patients have to go through to negotiate in their network. Our study showed that patients are not always actively creating and maintaining supportive networks and, within their existing networks, they had to deal with social norms and (family) relations. These barriers might explain why interventions that focus on changing social support have not always been successful. Although studies have found effects of social networks on health, improving health outcomes through interventions on social networks have shown less effect. Moreover, the struggles to maintain a social network and the potential negative effect of social comparison within family ties could explain why some social relations can even have a negative influence.

The process of creating and maintaining a social network was to some extent different for diabetes patients than for others. We found several indications that disease related factors influenced the interaction to the support network. For example respondents choose to interact with other diabetes patients to exchange information or, in another case, having complications caused by diabetes hindered the respondent to build reciprocal ties. Especially the latter was found in other studies showing that a poor health in older adults had a negative impact on their social relations, among others due to a lack of reciprocity.

Theoretically, our findings link to different approaches. The finding that engagement is important to people can provide an explanation for the effect of contagion. A person who is more embedded in a certain group (engagement), is more likely to adhere to the social norms (contagion) in this group. Following Durkheim, the effect of contagion will be stronger when the people in a network experience social engagement. This, however, does not mean that more engagement will show better self-management; social norms in a group are not always promoting the best health outcomes.

The presence of social comparison in our study can partly explain the effect of contagion. Studies have shown that when comparing with others who are better off, social comparison could result in better outcomes (e.g. stop smoking).
Our respondents indicated that providing support was important to them too. This relates to the results of a study that showed that only receiving support can enhance stress instead of providing positive effects\textsuperscript{33}. Therefore, to sustain long-term supportive relationships, providing support is just as important as receiving support. Our study showed that organisations and families could provide a platform to enhance reciprocity within a group. This type of exchange links to the concept of diffuse reciprocity\textsuperscript{34} which is common within families\textsuperscript{35}, but can be extended to groups and organisations and therefore these type of groups are helpful in the creation of supportive networks.

Finally, though studies have stressed the importance of selection mechanisms and influences from the social environment, our study indicates that selection is not always a controlled process and people are not aware of how their social environment influences them.

\textbf{Limitations}

While this study had the advantage of being completed in one country and therefore included fully translated transcripts with contextual factors, this also has the limitation that generalisability to other contexts might be limited. Especially factors related to social norms and roles are likely to be different in countries with for example stronger extended families instead of a nuclear family-centred society. The focus in this study for type 2 diabetes patients from a deprived area limits the findings in terms of generalisability further, but it provides a unique picture of a group that struggles most with maintaining stable blood glucose levels.

\textbf{Practical implications}

The structure of someone's network often is not the outcome of a balanced process. Therefore, creating a supportive network might not be likely for all diabetes patients. Moreover, maintaining a network takes a lot of capabilities. Interventions could focus on regularly involving close network members in diabetes related consultations. By involving these network members to a consultation at the GP, the effort of negotiating for the patients can be reduced and the support could become more efficient. Other interventions to improve someone's network should focus on the supportive role of (community) groups. These groups can provide a feeling of embeddedness and partly take away the need for capabilities to negotiate and navigate within a network.
Considering the fact that reciprocity is important when it comes to building a support network, interventions should take this aspect into account. Therefore, they should not only focus on how patients can be supported, but also on what kind of support they can provide in return.

Policies that advocate individual responsibility create the public discourse that patients 'have to do it themselves' and this way putting more stress on the process of negotiating and navigating. Instead of this, policies could place more emphasis on the importance of change in the broader environment, as a way of supporting individual and network efforts with self-management.
REFERENCES
Chapter 9

General discussion
This thesis focused on the social support networks of type 2 diabetes patients and their relation with self-management and health. In this final chapter we summarise and discuss the main findings of the studies in this thesis, reflect on the methodology used, and provide practical implications and directions for further research.

**MAIN FINDINGS**

Healthcare for people with a chronic disease is changing. **Chapter 2** showed that the macro-economic problems in the past years in combination with the prevailing ideology in society have led to a stronger emphasis on individual's self-management of health and disease. In fact, effective self-management is viewed as one of the cornerstones of current diabetes care. Individuals' personal social networks, community organisations, and an increase in the use of information technologies are seen as potential resources to facilitate this development. In this context, professional support of self-management is no longer exclusively delivered by health professionals, but provided by local coalitions of health and social care organisations with involvement of municipalities. In addition, individuals' support networks are expected to become more engaged. Poor reach of health programs in economically deprived areas was recognised as a potential risk factor, but has not led yet to targeted policies.

In **chapter 3** we provided hypotheses on determinants of self-management and health in individuals with diabetes, focusing on the role of social networks and community organisations. Theoretical perspectives, both from a social-constructivistic perspective and from a social networks approach were used for this. Based on these approaches, we suggested the mechanisms of social capital, engagement, social comparison, contagion, and reciprocity. Also, we described the design and methods of an international survey study in 6 European countries in terms of sampling, measures, and data-analysis.

**Chapter 4** concerned a methodological question: it assessed the effect of different monetary incentives on response rates to calibrate the optimal monetary incentive and this way to optimise data collection. The results showed that there was a nonlinear relationship between the amount of the monetary incentive and the response rate. Offering more money had positive impact on response rates but only up to a certain amount. Therefore, we concluded that high monetary incentives are not only inefficient but also less effective. We found no evidence for the hypothesis that monetary incentives have higher impact in deprived areas.

In **chapter 5** we examined the structure of the social networks of type 2 diabetes patients. We investigated which people provided support, their characteristics and relationships. We found that most social support networks were small in size (just over 3 members) and dense, with family members and women being highly represented. This indicates that close family and a spouse seem to be important to create and maintain a supportive network. Larger support networks were linked to more support, but less support per network member. Thus, a large sized network on its own is not necessarily an indicator of increased levels of support, but it can function in a way which reduces the burden for individual network members. Non-family links to
healthcare providers and community organisations were also linked to the provision of extra support. Differences between SES groups regarding network characteristics were small.

Both chapter 6 and 7 studied the relationship between network characteristics and health outcomes. In Chapter 6 we focused on patient-reported health status, physical exercise, diet and smoking. Overall, individual support network characteristics had mixed effects on health and behaviours. Participation in community organisations was most consistently related to better health status, especially strong in low-income populations. Contrary to this positive effect of community organisations, some of the positive impacts of the individual support network such as having a spouse and a larger information support network were not found in low-income populations. Low individual income itself had a negative effect on health and health-related behaviours and living in a deprived urban neighbourhood also had a negative impact on mental health status.

In Chapter 7 we studied the capabilities that are necessary for the self-management of someone’s disease. Looking at individual characteristics, both low education and income were negatively related to self-management capabilities. As in chapter 6, we found mixed effects of individual support networks. Only a large information network was consistently related to better self-management capabilities. This link was especially strong within the low education group, suggesting that people with a low education may benefit most from a large information network. On the other hand, larger emotional support networks showed a positive association better self-monitoring and insight, but especially in high education populations. Also, we found again a small positive effect of participation in community organisations. With the positive effect of a large information support network, this study provided an indication that strong social support may compensate for the adverse impact of low education.

Chapter 8 illustrated how patients themselves reflect on social networks and social support. Using a theory-driven approach and qualitative interviews, we found that social network mechanisms were prominent in the perceptions of our respondents. Both structural and functional theories were relevant to describe and explain how networks operate in diabetes patients. Using a structural view on networks, we found how patients reflected on forming and dissolving relationships, but that the establishment of a support network often was not considered a process that was within their control. Also, we were able to link the process of social comparison with both negative and positive effects of social contagion. Functional theories helped to understand what kind of efforts a patient needed to do in order to generate support from their network. The finding that topics related to negotiation often were mentioned showed that type 2 diabetes patients have a lot of social aspects that they have to deal with to create and sustain a supportive network. Restrictions on the potential for support were found in the feeling that having diabetes is something that people have to deal with alone and the limited capacity to reciprocate support due to poor physical capabilities.
METHODOLOGICAL CONSIDERATIONS

Whole systems
The research presented in this thesis was based on a ‘whole systems approach’\(^1\). This approach is associated with the use of multiple research methods and the inclusion of different perspectives by respondents with different roles. In terms of methodology, we used both quantitative and qualitative methods to create a comprehensive answer to our main objective\(^2\). The qualitative interviews with the key informants allowed us to identify items that were not yet well documented and the range of key informants added to the richness of the data. The quantitative studies provided information on the relationship between support networks, health, and deprivation. However, it is the qualitative study in chapter 8 that provided insight into how network mechanisms are perceived to work in everyday life of diabetes patients. Regarding the different perspectives, the inclusion of policy makers, managers, health-professionals and patients provided an overall view on the environment in which type 2 diabetes patients have to manage their disease.

Generalisability
The sampling of respondents in the quantitative study in this thesis was based on a random sample of type 2 diabetes patients within a purposeful selection of three areas in each of the six participating countries: a deprived urban area (e.g. an area in a city); a relatively affluent urban area; and a deprived (relative to country) rural area\(^3\). This sampling procedure has benefits as well as drawbacks. The choice to select areas close to each other resulted in a relatively homogenous sample and thus controlled for contextual factors (confounders related to area characteristics). This allowed us to study the effects of the deprivation and urbanisation of an area more clearly. On the other hand, this choice resulted in a sample that was not a representative set of areas for a larger region or country. Therefore, generalisation beyond chosen areas and countries was not possible. Although this limits the conclusions based on descriptive statistics, the conclusions based on the relationships that we found are less affected by this. Because the underlying theoretical mechanisms responsible for these relationships are generic, we would suggest that the conclusions based on these findings have a broad external validity to other areas\(^4\).

Limitations
One of the hypotheses in the beginning of the project was that social support could potentially compensate for the adverse health effects of deprivation and austerity. However, the cross-sectional design restricts causality claims. Without multiple measurements in time, we could only test the correlation of social support and deprivation at one moment in time. Whether an increase in deprivation had less effect on health outcomes when someone had more social support was therefore not directly testable. However, to thoroughly study the effects of
economic and social network changes will need a time span of several years which was not feasible in this study.

Studying structural characteristics of small networks was limited by the high correlation between the different network characteristics, and between some of these network characteristics and the amount of support. This correlation made it impossible to test all relationships simultaneously and restricts conclusions about the effect of structural network characteristics on the amount of support.

The study on key informants used a flexible approach and although attempted, we were not able to include stakeholder from relevant industries e.g. food industry. Therefore, this study could not provide a comprehensive overview of all themes related to diabetes. However, we believe that the included respondents covered most of the relevant stakeholders.

**INTERPRETATION OF FINDINGS**

*Health inequity in times of austerity policies*

This study was conducted in a period in which European countries faced the consequences of major cuts in public services due to the economic recession in 2009. These cuts are known as austerity measures and also affected health services. Although the implications of austerity policies dramatically differed between European countries, they played in many settings an important role in shaping the context in which our respondents had to cope with their disease. These measures had most impact on lower socioeconomic status (SES) groups, because they rely more on public services and thus potentially increasing health inequalities. Long-term conditions that are related to lifestyle, such as type 2 diabetes, are one of the origins of this health inequity. This inequity in diabetes is multifactorial. First, low SES groups have an increased risk of developing diabetes. And, when diagnosed with diabetes, they have a poorer control of their disease. Also, existing educational and behaviour change programs for chronic conditions have less impact amongst low SES groups. And finally, the recent austerity measures have affected low SES groups more than affluent populations, increasing the differences between groups even more. The current trend in policies which emphasises self-responsibility is unlikely to put a hold on the health-inequality between SES groups because lower SES populations have less individual, social, and financial resources to draw on. Therefore, reducing health-inequalities remains a challenge.

In this thesis we indeed found negative effects of low SES and (deprived) neighbourhoods on health. Moreover, some of the personal support network characteristics were less beneficial for low SES groups than they were for patients with a higher SES. This suggests that enlarging patients' networks as a mean to improve health outcomes may mostly provide benefit for higher SES groups. Thus, policies that rely on the potential of social networks might not be sufficient to reduce health inequalities. On the other hand, we also found some starting points to use social networks to improve health outcomes for deprived diabetes patients. Chapter 7 shows that a
large information network was related to better self-management capabilities in low SES populations and in both chapters 6 and 7 was found that participation in community organisations was positively related to health indicators\textsuperscript{16,17}. These findings provide an opportunity to reduce health inequity. When interventions to increase participation in community organisations are deployed, they should be targeted on deprived neighbourhoods to improve wellbeing for these populations.

**Self-management in a broader context**

Although we focussed on type 2 diabetes, we believe that some of our findings apply to a broader context. Other non-communicable, chronic diseases, such as cardiovascular diseases (CVD) and chronic obstructed pulmonary disease (COPD), face similar challenges. The incidence of these diseases is increasing worldwide, partly because of common modifiable risk factors. These risk factors e.g. unhealthy diet, physical inactivity and tobacco use, are comparable to type 2 diabetes and request similar lifestyle changes which are guided by self-management programs. We will discuss how our results apply to cardiovascular diseases and COPD and what it means for their treatment.

Cardiovascular diseases were responsible for 17.5 million deaths worldwide in 2012\textsuperscript{18}, affecting mostly patients above 75 year. Besides familial risk and age, lifestyle related factors e.g. diet, physical exercise, obesity, and tobacco are risk factors for developing CVD. Also diabetes itself is an important risk factor for CVD. Treatment consists of drug therapy using diuretic and ACE inhibitors and beta-blockers, but also include educational and lifestyle interventions. These lifestyle interventions are based on self-management and target weight(loss), taking medication, diet, smoking behaviour, and physical exercise. COPD affects about 2\% of the Dutch population and is often caused by smoking behaviour. Independently of smoking, low socioeconomic status was also related to a higher incidence\textsuperscript{19}. COPD management focuses on limiting symptoms, improve exercise capacity and quality of life, and reduce the burden of disease\textsuperscript{20}. To achieve this, besides inhaled medication, stop smoking and physical exercise are the main components.

In terms of self-management behaviour, especially the positive link between participating in community organisations and health-related lifestyles such as physical activity and smoking is very relevant for both CVD and COPD patients. And even more because the relationship between physical activity and participation in community organisations was especially strong in lower SES groups. Necessary capabilities for self-management have relevance across different chronic diseases and could be improved by extending patients' information networks, especially in lower SES groups. And although our findings were based on a specific population of type 2 diabetes patients, we think that COPD and CVD affects similar people, with the same overrepresentation of lower SES groups.

We illustrated that the possibility to receive support from a social network is relevant across chronic diseases. However, in a more general way, social support becomes relevant when patient's ability to function independently is affected. Therefore, we can state that receiving
social support has also importance to aging people in general. Taking our findings into account that current support networks strongly rely on the presence of a spouse and/or close family, it seems important to keep investing in new social relationships because this group becomes smaller when people get older. This implies especially for elderly that they might have to invest in social contacts when they still have the physical capabilities to do this. How to prevent loneliness among elderly is a current ongoing debate\textsuperscript{21}, but the importance of reciprocal relationships tells us that especially elderly will have to keep investing in durable relationships because their network becomes less dense. This should be emphasized by policies, as we also found that people take their social networks for granted and do not consider it something within their control (chapter 8). Non-family related links to community organisations could potentially provide an extra link to the provision of extra support.

**Distribution of roles: professional, community, and individual level**

Discussing the social environment in which patients had to deal with their condition also raises the question how roles and responsibilities in the management of health and disease are distributed. The current Dutch guideline indicates that health-professionals, often a GP or diabetes nurse, are responsible for the initial course of treatment and an annually review of this treatment\textsuperscript{22}. Besides the care and support provided at general practices, other (health) professionals can be included to provide support, e.g. physiotherapists and dieticians\textsuperscript{23}. Because living with diabetes involves lifestyle changes which mostly take place in the daily life, also patients have to take an active role in the management of their disease. This is established in the notion of self-management, which can be defined as the care taken by individuals towards their own health and well-being\textsuperscript{24}. Self-management of health and disease is not a task patients have to do on their own; health professionals often have a role in supporting patients in the management of their diseases. It involves the training of patients in skills and techniques to successfully manage their disease: leading a healthy lifestyle, meeting their social, emotional and psychological needs, and preventing further illness or accidents. This self-management support (SMS) is a core feature of the chronic care model (CCM)\textsuperscript{25} and is considered an important part of the care provided by a GP and diabetes nurses.

So far we have described the healthcare for diabetes patients as an interaction between professional healthcare providers and patients. However, this perspective does not take into account the potential of a broader approach that also includes non-professionals in the support for diabetes patients\textsuperscript{26}. Increasingly, non-professionals and community resources are considered valuable recourses to support the self-management of patients with a long-term condition, but how they should be included is not yet specified.

In this thesis we showed that personal networks, such as family and friends, provide another source of support. Some network characteristics are associated with better self-management such as having a larger information network or a spouse. This is supported by a recent review
which showed that non-professionals play an important role in improving the quality of life for people living with diabetes or other chronic conditions. However, we also illustrated that these personal networks are not always beneficial, especially in low SES groups. Because these networks are often characterised by a high degree of homophily (high similarity between people), they might be able to provide support, but may not be the catalyst for behaviour change. Considering this, expecting too much of the individual patient and his/her network might disadvantage those groups and increase health inequalities. Therefore, healthcare professionals still have to take the responsibility to provide optimal care for these patients. However, for the better or worse, the fact that individual networks have an influence on patients' self-management should have consequences for practice guidelines. Even if it is considered difficult to assign them formal roles, their influence on patients' behaviour makes it important to involve them in the treatment.

We also found a consistent role for support from community organisations; participation in community organisations was related to better self-management. Including those organisations in the care for diabetes patients could result in better health outcomes. Other research has shown that community based resources can provide assistance and support and bridge the communication gap between patients and their health care providers, especially when it comes to communities where access to professional health services is limited.

Although the relevance of including community organisations is high and the current guideline of the Dutch Diabetes Federation mentions a multidisciplinary approach, this guideline is still restricted to professional health providers. A barrier in this process might be that it is not yet clear how structural referral pathways can be built that involve both professional health care providers and community based resources. A one size fits all approach might not work with this type of organisations. And although we argue that optimal care should not be restricted solely to the (health) professional domain, there are some more limitations to include other domains. When it comes to include community organisations and personal networks, it is often difficult to transfer responsibilities. An important restriction is that those organisations rely on volunteers for a substantial amount. This limits the possibility to assign them a formal role in the care for diabetes patients. Another important issue is the sustainability of support programs that are led by volunteers. Although several studies have shown the effectiveness of these programs, health policies providing financial support are necessary to sustain them in the long run.

Health networks in practice

Recently, projects have been developed that use social network ideas to improve health outcomes with promising results. For example, a recent lifestyle intervention that is partly based on social connections is EuroFIT. This program uses online games, social networks and peer support to motivate the participants to increase their physical activity. The social network component links to different network mechanisms described in this thesis; engagement is created by linking the intervention to a professional football club, social support is created by
stimulating participants to meet outside the intervention, and social comparison is used by drawing attention to others' performance to explicitly elicit comparisons\textsuperscript{31}. Another intervention that recently was developed is EU-GENIE. As part of the EU-WISE project, but beyond the scope of this thesis, this social network intervention was developed to improve patient networks. EU-GENIE is based on findings throughout the EU-WISE project including parts of this thesis. This intervention comprised the mapping of personal networks, the assessment of patient needs and interest, and the provision of links to community organisations to meet the patient's needs. Especially the link with community organisations was informed by the results from chapter 6 and 7 in this thesis\textsuperscript{16,17}. Assessment of the EU-GENIE intervention showed that talking about patient's personal network raised awareness of the potential support available in his/her network. Although participants were cautious about changing their network composition, linking to community organisations was perceived as the most feasible change. Several countries are planning to bring (aspects) of EU-GENIE into practice for a broader group of users.

\textit{Reflection on theories}

We used several theoretical perspectives to understand how social context influences self-management and quality of life in people with long term conditions. We will discuss the social capital theory and a structural perspective on networks and elaborate how these perspectives relate to our findings.

The notion of social capital is based on the idea that someone's personal success not only depends on personal treats such as education and income, but that social factors also have an impact on this. These social factors can belong to the individual in the form of access to people and entities with relevant resources, or as part of resources embedded in a neighbourhood or society as whole. We applied this theoretical notion by considering good self-management and a high quality of life as personal success. Social factors that were considered to contain social capital were factors related directly to the individual's network, such as access to people or entities with relevant resources as well as the quality of relationships at the level of neighbourhoods and society as a whole\textsuperscript{32,33}.

Our findings showed that community organisations were beneficial for health related outcomes, especially in low SES groups provides support for the social capital theory; patients with more social capital (community organisations) had better health outcomes. Within the individual networks we did not measure the available resources in a network, so we cannot draw clear conclusions on those. However, the finding that larger information networks were related to better self-management indicates that social capital in the form of information resources was beneficial. And if we assume that the quality of information is better in high-SES group networks, the finding that the relationship between information network size and self-management is stronger in high-SES groups emphasizes that social capital can provide an explanation for health
Whereas social capital focuses on the resources embedded in personal relationships and within societies, the structural perspective focuses on the structure of the relationships that people have. Its starting point is the observation that individual networks are not created randomly, but are shaped by processes of (social) selection of network members and contagion of ideas and behaviours in the network. The process of social selection tries to explain how ties between people are formed and dissolved. And although this method is essentially data driven and therefore one cannot derive specific predictions, it provided a methodology and proof to show the tendency towards homophily in networks. Homophily being "the principle that a contact between similar people occurs at a higher rate than among dissimilar people". Contagion is based on the idea that people who are somehow related tend to influence one another. This way, attitudes and behaviour spread through social networks, as if they were infectious diseases. Both contagion and selection processes define the structural layout of a network and are therefore important for the potential of support that is available in a network.

In our qualitative study, we found that the selection of network members is often not an active process and also that many people are not aware of how their social environment influences them. This does not mean that the theory is incorrect; however, it limits the possibility to use these theoretical perspectives to improve health outcomes, in situations where individuals' awareness of the role of the social environment is relevant. Without people being aware of network-related processes, it will be hard to change them. Our finding that family members made up the largest part of support networks underlines this, as family members are not completely freely chosen (chapter 5). The quantitative part of this thesis used a cross-sectional design, which cannot tell whether this homophily was caused by selection or contagion effects. To study this, a longitudinal design would be necessary.

Combining both the social capital and structural theoretical perspectives could provide an explanation why individual networks are less beneficial for low SES groups. The structural perspective explains that network members are similar to the ego and thus likely to have fewer resources. The social capital theory explains how this lack of social capital affects their self-management.

**FUTURE DIRECTIONS**

*Policy and practice*

The results of the studies in this thesis have several implications for practice. At a health policy level, the view that effective self-management is the cornerstone of diabetes care and should be facilitated by individuals' social networks and community organisations has implications for the organisation of health care. Instead of including only professional health providers in a
multidisciplinary team, also local community organisations and patients’ network should be included in order to create local coalitions of health and social care organisations. Only in this way, patients can receive full support to manage their diabetes in a day-to-day setting. Besides their contribution as part of a multidisciplinary approach to diabetes cares, we showed that community organisations also have a more direct positive influence on diabetes patients. Participating in community organisations was related to better health status and self-management capabilities. These effects are not only achieved by the specific activities (e.g. walking at a walking club), but also because these organisations and activities offer a platform to meet other people. Increasing individual networks this way might increase the variety in resources in a network. Therefore, health professionals and policy makers should increase the support to community organisations, which offer activities that are relevant for the self-management of health in people with chronic diseases. From a patient perspective, interventions should be developed to increase patient participation in these types of organisations. Enlarging individual support networks to improve patients’ self-management and health outcomes should be considered carefully because the relevance of having a large number of connections was mixed and overall limited. If interventions to enlarge individual social networks are designed they should address strengthening the informational and emotional support networks because these networks may be able to compensate for the adverse effects of deprivation. However, because of the limited evidence for interventions to increase the size of individual support networks, they need to be applied on the basis of individual judgement rather than taken as the given goals of public health policies. Instead of enlarging networks, a more feasible option to increase support in social networks might be to improve the quality of existing support networks. Interventions targeted on patients with a chronic condition should involve his/her social network to maximise its effect. Examples of this include the involvement of patients’ partners and groups in self-management support interventions. Increasing the size of support networks may not necessarily result in more support, but it can reduce the burden for individual network members.

Research
In this thesis we provided insight in the relation between social networks and health outcomes and the underlying mechanisms. However, there are still some remaining topics that need to be uncovered to provide the best support for patients with type 2 diabetes.

Study design
The cross-sectional design of our study can only show relationships between social networks and health (related) outcomes. And although we tried to make causality plausible by using a regression model controlling for multiple factors, a different study design is necessary to prove causality. Future studies should therefore address this by using a longitudinal study design to
study how changes in social networks and social support affect patients’ self-management and health.

**Differences in social networks**

Although we provided an extensive overview of how social support networks are related to health and self-management, we could not cover all subjects in this thesis. A remaining issue is how social support networks differ between specific populations and individual characteristics. In this thesis we focused on differences in income and education as indicators for socioeconomic status, which provided some implications for health policies and information to design interventions that address differences in SES. However, (the effect of) social support networks may also differ between patient characteristics such as gender, age, and severity of illness. More insight in the differences in social networks between these groups could provide a better starting point to optimise the support for each individual person. Some indication is already provided by a study that showed that non-white and more affluent participants received slightly higher amounts of everyday work support, however effects on illness related and emotional support were not found\(^{36}\). Another study showed that women have larger and more supportive networks than men\(^{37}\), but without linking this to health-related outcomes.

**Developing and testing interventions that can improve patients’ networks**

A second topic that should be addressed is how social support networks can be enhanced. This thesis indicates that patients are sometimes reluctant to change their social network actively, because they are happy the way it is or just take their network as given\(^{28}\). Therefore, it seems hard to design interventions that successfully can enlarge patients’ networks or change its structure. Existing interventions to improve social support found mixed results; a review on social support interventions could not clarify which aspects of social support were most effective for enhancing self-management and outcomes of care for people with type 2 diabetes\(^{38}\). This thesis provided information for the development of a concept for a social network intervention. However, social networks are specific for each individual and interventions need to be tailored to the specific characteristics and needs of the patient. Therefore, more research on the development of successful interventions targeting social support is necessary.

**FINAL CONCLUSION**

In the thesis we studied the characteristics of social support networks and tried to gain insight in the relationship between social networks and self-management within type 2 diabetes patients. We found that individual social networks can be supportive, but larger networks are not necessarily more beneficial. To enhance patients’ networks and improve health-related outcomes, community organisations could play a central role.
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Summary
Chapter 1
In chapter 1 we present the background, main objectives and structure of this thesis. This thesis aims to provide insight into the role of social support networks in self-management of health and disease in diabetes type 2 patients, with a particular focus on people with socioeconomic deprivation. Specific objectives are:

- To identify emerging policies and practices regarding diabetes care in The Netherlands.
- To explore the structural characteristics of social support networks of type 2 diabetes patients and the association with the volume of social support received.
- To examine the impact of different types of support and social networks on self-management capabilities, health, and health-related behaviours in patients with type 2 diabetes.
- To explore which theory-based mechanisms are relevant to type 2 diabetes patients in generating a social support network.

Chapter 2
The aim of chapter 2 is to identify emerging policies and practices regarding diabetes care in The Netherlands. We selected a purposeful sample of 15 key informants, covering a range of stakeholders, which were interviewed using a semi-structured approach. A thematic analysis was done, guided by an pre-defined framework. We showed that the macro-economic problems in the past years in combination with the prevailing ideology in society have led to a stronger emphasis on individual's self-management of health and disease. In fact, effective self-management was viewed as one of the cornerstones of current diabetes care. Individuals' personal social networks, community organisations, and an increase in the use of information technologies are seen as potential resources to facilitate this development. In this context, professional support of self-management is no longer exclusively delivered by health professionals, but provided by local coalitions of health and social care organisations with involvement of municipalities. In addition, individuals' support networks are expected to become more engaged. Poor reach of health programs in economically deprived areas was recognised as a problem, but has not led yet to targeted policies.

Chapter 3
In chapter 3 we described the protocol of a cross-sectional study covering 18 geographic areas in six European countries (Bulgaria, Greece, Netherlands, Norway, Spain, and the United Kingdom) which involved a total of 1,800 individuals with diabetes and 900 representatives of community organisations. The development of the questionnaire was described, which included measures for quality of life, self-management behaviours, social network and social support, as well as individual characteristics. From a theoretical perspective, we developed hypotheses on determinants of self-management and health in individuals with diabetes, focusing on the role of social networks and community organisations. Theoretical perspectives, both from a social-constructivistic perspective and from a structural social networks approach were used for this.
Based on these approaches, we suggested the mechanisms of social capital, engagement, social comparison, contagion, and reciprocity.

Chapter 4
In chapter 4 we discuss a methodological question: what is the effect of different monetary incentives on response rates? We performed a patient-randomised trial in which targeted individuals received different gift vouchers (€5.00, €7.50, €10.00, and €12.50) on completion of a survey and interview. The results showed that there was a nonlinear relationship between the amount of the monetary incentive and the response rate. Offering more money had positive impact on response rates but only up to a certain amount. Therefore, we concluded that high monetary incentives are not only inefficient but also less effective. We found no evidence for the hypothesis that monetary incentives have higher impact in deprived areas.

Chapter 5
Chapter 5 examines the structure of the social networks of type 2 diabetes patients and the variation between high and low socioeconomic status groups. We investigated which people provided support, their characteristics and the relationships between them. The study was based on a cross-sectional design and data were collected with questionnaires and subsequent interviews. Multilevel regression modelling was used to assess the effect of structural network characteristics on the volume of social support. In total, 1,692 respondents completed the questionnaire and interview. We found that most social support networks were small in size (just over 3 members) and dense, with family members and women being highly represented. This indicates that close family and a spouse seem to be important to create and maintain a supportive network. Larger support networks were linked to more support, but less support per network member. Non-family links to healthcare providers and community organisations were also linked to the provision of extra support. Differences between SES groups regarding network characteristics were small.

Chapter 6
The aim of chapter 6 was to examine the relative impact of different types of support on health and health-related behaviours in patients with type 2 diabetes. We performed an observational study in a sample of 1,692 type 2 diabetes patients with 5,433 connections. Outcomes were patient-reported health status, physical exercise, and diet and smoking. We used multilevel regression modelling to assess the effect of social support and education on health (behaviour) outcomes. We found that overall, individual support network characteristics had mixed effects on health and behaviours. Participation in community organisations was most consistently related to better health status, especially strong in low-income populations. Contrary to this positive effect of community organisations, some of the positive impacts of the individual support network, such as having a spouse and a larger information support network, were not
found in low-income populations. Low individual income itself had a negative effect on health and health-related behaviours and living in a deprived urban neighbourhood also had a negative impact on mental health status.

**Chapter 7**

In chapter 7 we studied the capabilities that are necessary for the self-management of a chronic disease. The aim was to explore which aspects of social networks are related to self-management capabilities and whether these networks have the potential to reduce the adverse health effects of deprivation. The used methods were similar to chapter 6. We found that, by looking at individual characteristics, both low education and income were negatively related to self-management capabilities. As in chapter 6, we found mixed effects of individual support networks. Only a large information network was consistently related to better self-management capabilities. This link was especially strong within the low education group, suggesting that people with a low education may benefit most from a large information network. On the other hand, larger emotional support networks showed a positive association better self-monitoring and insight, but especially in high education populations. Also, we found again a small positive effect of participation in community organisations. With the positive effect of a large information support network, this study provided an indication that strong social support may compensate for the adverse impact of low education.

**Chapter 8**

The aim of chapter 8 was to explore through empirical testing which theory-based mechanisms are relevant to diabetes patients in generating a social support network. By illustrating how patients reflect on social networks and social support, we compared structural and functional sociological theories on their relevance for explaining how support is generated. We conducted a qualitative study using semi-structured interviewing within 25 type 2 diabetes patients in The Netherlands. The interviews used a biographical approach and covered topics about the social support they received. Data were analysed using a framework method. We found that social network mechanisms were prominent in the perceptions of our respondents. Both structural and functional theories were relevant to describe and explain how networks operate in diabetes patients. Using a structural view on networks, we found that patients reflected on forming and dissolving relationships, but this was often an unreflexive process. Social comparison was linked to both negative and positive effects of social contagion. Functional theories helped to understand the patients’ efforts to generate support from their network. Negotiating support was often mentioned and perceived to be guided by social norms. The feeling that diabetes is something they have to deal with alone and the limited capacity to reciprocate support are barriers for the potential to generate support.
Chapter 9
In this chapter we present the general discussion of this thesis. We summarise the main findings, discuss methodological considerations, interpret our findings in a broader context, and discuss the implications for policy, practice and future research. By studying the characteristics of social support networks we gained insight in the relationship between social networks and self-management within type 2 diabetes patients. We found that individual social networks can be supportive, but larger networks are not necessarily more beneficial. To enhance patients' networks and improve health-related outcomes, community organisations could play a central role.
Samenvatting
Hoofdstuk 1
In hoofdstuk 1 presenteren we de achtergrond, het hoofddoel en de opbouw van dit proefschrift. Dit proefschrift heeft als doel om inzicht te geven in de rol van sociale steun netwerken met betrekking tot zelfmanagement bij patiënten met diabetes type 2, waarbij we specifiek focussen op mensen met een lage sociaaleconomische status. Specifieke doelen zijn:

- Het identificeren van veranderingen in beleid met betrekking tot de zorg voor diabetes in Nederland.
- Het verkennen van de structurele kenmerken van sociale netwerken voor patiënten met diabetes type 2 en hun relatie met de omvang van de ontvangen sociale steun.
- Het testen van de invloed van verschillende typen van sociale steun netwerken op zelfmanagement vaardigheden, gezondheid en gezondheidsgereleateerd gedrag bij patiënten met diabetes type 2.

Onderzoeken welke theoretisch onderbouwde mechanismen van toepassing zijn voor hoe diabetes type 2 patiënten hun steun uit hun sociale netwerk genereren.

Hoofdstuk 2
In hoofdstuk 2 is het doel om veranderingen in het beleid met betrekking tot de zorg voor diabetes in Nederland te identificeren. Hiervoor selecteerden we door middel van een doelgerichte steekproef 15 informanten met relevante functies op het gebied van diabetes. Deze informanten zijn geïnterviewd door middel van een semi-gestructureerde methode. De interviews zijn thematische geanalyseerd met gebruik van een vooraf gedefinieerd framework.

Uit deze analyse bleek dat de macro-economische problemen van de laatste jaren in combinatie met dominante ideologie in de samenleving ertoe geleid hebben dat er meer nadruk is gekomen op de individuele verantwoordelijkheid voor zelfmanagement met betrekking tot gezondheid. In feite werd effectief zelfmanagement gezien als een van de hoekstenen voor de huidige diabetes zorg. Sociale netwerken van mensen, maatschappelijke organisaties en een toename van informatie technologie worden gezien als mogelijke manieren die deze ontwikkeling mogelijk moeten maken. In deze context is professionele steun voor zelfmanagement niet langer het exclusieve domein van zorgprofessionals, maar wordt dit ook verzorgd door lokale samenwerkingsverbanden van sociale- en gezondheidsorganisaties met betrokkenheid van gemeentes. Hiernaast wordt van persoonlijke steunnetwerken meer betrokkenheid verwacht. Het beperkte bereik van gezondheidsprogramma’s in achterstandsgebieden werd als een probleem ervaren, maar dit heeft nog niet tot specifiek beleid geleid.

Hoofdstuk 3
In hoofdstuk 3 beschrijven we het protocol voor een cross-sectionele studie in 18 geografische gebieden in zes Europese landen (Bulgarye, Griekenland, Nederland, Noorwegen, Spanje en het Verenigd Koninkrijk) met 1800 mensen met diabetes type 2 en 900 vertegenwoordigers van
Samenvatting

maatschappelijke organisaties. We beschrijven de ontwikkeling van de vragenlijst, welke indicatoren bevat voor kwaliteit van leven, zelfmanagement gedrag, sociale netwerken en sociale steun, en achtergrondkenmerken. Vanuit een theoretisch perspectief ontwikkelden we hypothesen over de determinanten voor zelfmanagement en gezondheid voor mensen met diabetes met nadruk op de rol van sociale netwerken en maatschappelijke organisaties. Hiervoor gebruikten we theoretische uitgangspunten, van zowel een sociaal-constructivistisch perspectief en van een structurele benadering van sociale netwerken. Gebaseerd op deze benaderingen beschrijven we de mechanismen van sociaal kapitaal, betrokkenheid, sociale vergelijking, besmetting en reciprociteit.

Hoofdstuk 4
In hoofdstuk 4 behandelden we een methodologisch vraagstuk: wat is het effect van verschillende niveaus van financiële vergoedingen op de respons bij een enquête? Hiervoor voerden we een patiënt gerandomiseerde trial uit waarbij mensen verschillende waardebonnen (€5.00, €7.50, €10.00 en €12.50) ontvingen bij het afronden van een vragenlijst en interview. De resultaten laten zien dat er een niet-lineair verband is tussen de hoogte van de vergoeding en de mate van respons. Meer geld bieden had een positief effect, maar alleen tot een bepaalde hoogte. Daarom concludeerden we dat hoge financiële vergoedingen niet alleen inefficiënt zijn, maar ook minder effectief. We vonden geen bewijs voor de hypothese dat financiële vergoedingen meer effect hebben in achterstandsgebieden.

Hoofdstuk 5
In hoofdstuk 5 onderzochten we de structuur van sociale netwerken van patiënten met diabetes type 2 en de variatie hierin tussen hoge en lage sociaaleconomische status groepen. We onderzochten welke mensen steun verleenden, hun kenmerken en de relaties tussen hen. Voor het onderzoek verzamelden we cross-sectionele data met behulp van vragenlijsten en opvolgende interviews. Door middel van multilevel regressie analyse schatten we het effect van structurele netwerk kenmerken op de omvang van de ontvangen sociale steun. In totaal deden 1692 mensen mee met de vragenlijst en het interview. We vonden dat de meeste sociale steun netwerken klein waren (iets meer dan 3 leden) en hecht, met veel contact onderling. Familie leden en vrouwen waren oververtegenwoordigd in deze steun netwerken. Dit duidt erop dat nabije familie en partners een belangrijke rol lijken te spelen bij het opbouwen en onderhouden van een netwerk met veel steun. Groteren netwerken leverden meer steun, maar met relatief minder steun per netwerklid. Contacten buiten de familie met zorgverleners en maatschappelijke organisaties waren ook gelinkt aan het ontvangen van meer steun. Verschillen tussen sociaaleconomische status groepen met betrekking tot netwerk kenmerken waren over het algemeen klein.
**Hoofdstuk 6**
Het doel van hoofdstuk 6 was om het relatieve effect van verschillende soorten van steun op iemands gezondheid en gezondheidsgerelateerd gedrag te onderzoeken. Hiervoor voerden we een observationele studie uit in een steekproef van 1692 patiënten met diabetes type 2 die samen 5433 contacten rapporteerden. Als uitkomsten keken we naar de zelf-gerapporteerde ervaren gezondheid, mate van beweging, dieet en rookgedrag. We gebruikten een multilevel regressie analyse om het effect van sociale steun en opleiding op iemands gezondheid te onderzoeken. Hieruit bleek dat sociale steun netwerken een wisselend effect hadden op iemands gezondheid en gerelateerd gedrag. Participatie in maatschappelijke organisaties was het meest consistent gelinkt aan een betere gezondheid, met name in groepen met een lager inkomen. In tegenstelling tot dit positieve effect van maatschappelijke organisaties, vonden we dat sommige van de positieve effecten van sociale steunnetwerken, zoals het hebben van een partner en meer leden die informatie verstrekken, niet aanwezig waren in groepen met een laag inkomen. Het hebben van een laag inkomen op zichzelf had ook een negatief effect op gezondheid en gerelateerd gedrag, net als dat het wonen in een achterstandsbuurt een negatief effect had op iemands mentale gezondheid.

**Hoofdstuk 7**
In hoofdstuk 7 onderzochten we de vaardigheden die nodig zijn voor het omgaan met een chronische ziekte. Het doel was om te onderzoeken welke sociale netwerk aspecten gerelateerd zijn aan zelfmanagement vaardigheden en of deze netwerken mogelijk de negatieve effecten van deprivatie kunnen compenseren. De gebruikte methoden zijn vergelijkbaar met hoofdstuk 6. Wat betreft individuele kenmerken vonden we dat zowel een lage opleiding als een laag inkomen negatief gerelateerd waren aan zelfmanagement vaardigheden. Net als in hoofdstuk 6 vonden we wisselende effecten van sociale steunnetwerken. Enkel een groot informatie netwerk was consistent gelinkt aan betere zelfmanagement vaardigheden. Deze link was met name sterk aanwezig in de groep met een lage opleiding, wat er op duidt dat mensen met een lage opleiding het meeste profiteren van een groot informatie netwerk. Aan de andere kant, grotere emotionele steun netwerken waren juist meer gelinkt aan bepaalde zelfmanagement vaardigheden in groepen met een hogere opleiding. Ook vonden we wederom een klein positief effect van het participeren in maatschappelijke organisaties. Met het positieve effect van grotere informationetwerken duidt deze studie erop dat een sterk sociaal netwerk mogelijk een bijdrage kan leveren aan het compenseren voor de negatieve effecten een lage opleiding.

**Hoofdstuk 8**
Het doel van hoofdstuk 8 was het onderzoeken welke theoretisch onderbouwde mechanismen relevant zijn voor diabetes patiënten als het gaat om het genereren van een sociaal steunnetwerk. Door te laten zien hoe patiënten reflecteren op sociale netwerken en sociale steun, vergeleken we structurele en functionele sociologische theorieën op hun relevantie voor
het verklaren hoe sociale steun tot stand komt. Hiervoor voerden we een kwalitatieve studie uit met semi-gestructureerde interviews met 25 diabetes type 2 patiënten in Nederland. De interviews waren gebaseerd op een biografische aanpak en bevatten onderwerpen met betrekking tot de sociale steun die mensen ontvingen. De data is geanalyseerd met behulp van de framework methode. We vonden dat sociale netwerk mechanismen duidelijk aanwezig waren in de perceptie van onze respondenten. Zowel de structurele als functionele theorie was relevant bij het beschrijven en verklaren hoe netwerken werken bij patiënten met diabetes. Vanuit het structurele perspectief vonden we dat patiënten reflecteerden op het aangaan en verbreken van relaties, maar ook dat dit vaak een onbewust proces was. Sociale vergelijking was gelinkt aan zowel negatieve als positieve effecten van sociale beïnvloeding. De functionele benadering droeg bij aan het begrijpen hoe patiënten steun genereren uit hun netwerk. Het onderhandelen over steun werd vaak genoemd, een proces wat vaak werd gestuurd door sociale normen. Het gevoel dat diabetes is iets wat men zelf moet oplossen en de beperkte mogelijkheden om zelf steun te kunnen geven zijn barrières voor de mogelijkheden om meer steun te genereren.

**Hoofdstuk 9**

In dit hoofdstuk presenteren we de discussie van dit proefschrift. We vatten de hoofdbevindingen samen, bediscussiëren de methodologische afwegingen, interpreteren onze bevindingen in een bredere context en reflecteren op de implicaties voor beleid en toekomstig onderzoek. Door het onderzoeken van de kenmerken van sociale steun netwerken hebben we inzicht verkregen in de relatie tussen sociale netwerken en zelfmanagement bij patiënten met diabetes type 2. We vonden dat individuele netwerken kunnen ondersteunen, maar dat een groter netwerk niet altijd meer oplevert. Om de netwerken van diabetes patiënten en hun gezondheid te verbeteren zouden maatschappelijke organisaties een grotere rol kunnen spelen.
Dankwoord
Voor mijn dankwoord moet ik beginnen bij het begin. In dit geval mijn begin bij IQ healthcare. Of was het toen nog WOK? Het is ook al weer even geleden. Helemaal uitputtend kan ik dus niet zijn, daarvoor heb ik te lang op deze afdeling rondgelopen. Het is echter wel belangrijk deze periode te benoemen, want zonder deze voorafgaande periode was deze promotie er ook nooit gekomen, omdat ik in deze periode veel geleerd heb.

Het begon ermee dat tijdens het schrijven van mijn afstudeerscriptie voor de sociologie opleiding een mailtje rondgestuurd werd met de vraag dat er iemand werd gezocht om analyses uit te voeren op het UMC (dank daarvoor Maarten). Dit heb ik niet afgeslagen en zo zat ik weldra bij Michel op de kamer waar hij uitlegde dat hij graag netwerken in kaart wilde brengen door middel van statistische methoden. Door het naar beide wens uitvoeren van deze taken, kreeg ik de mogelijkheid na mijn afstuderen direct als onderzoeksmedewerker op de afdeling aan de slag te gaan.

Als onderzoeksmedewerker heb ik mogen werken onder de enthousiaste leiding van Annelies, samen met veel leuke collega's in het team met onderzoeksmedewerkers, ook bekend als TOAST, TOM, RS, eh dat was het? Wat betreft collega's zat het ook meteen goed met toppers zoals Geertje, Marjan, Marc en Ellen. Die tijd erg genoten van de lol naast onze werkzaamheden, zoals tafeltennissen in de pauzes en het maken van goede, maar vooral ook veel slechte grappen waarvan sommige nog steeds in ere worden gehouden.

Ook een mooie tijd heb ik gehad op een kamer met Anita, Carla en Irma. Naast het delen van elkaars wel en wee ook veel plezier gehad. Wat dit betreft wil ik graag een gebeurtenis aanhalen waarbij Anita, alsof het een honkbal wedstrijd was, een mandarijntje aangooide, waarna ik hem probeerde raak te trappen. Dit soort ongevallen was altijd erg verfrissend aan het einde van een dag werken.

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Als laatste rustplaats ben ik tenslotte beland in de flexkamer. Samen met Nelleke hielden we zowel orde in de kamer als binnen Schil, de vertegenwoordiging van junioren binnen IQ. Ik vond dat we een mooi team vormden Nelleke! Na Nelleke’s vertrek nam Annelie haar plaats over als vaste bezetting in een verder door vooral parttimers bevolkte kamer. Gelukkig bleek je een
meer dan een volwaardige vervanging te zijn. We hadden een beetje vergelijkbaar werkritme en je had een goede invloed op me omdat je me er regelmatig op wees dat ik me niet moest aanstellen en me een schop onder de kont gaf. Ik denk dat we een goed team waren en super samenwerkten wat betreft het creëren van een goede sfeer op IQ! Ook wil ik graag Guus bedanken voor zijn mannelijke inbreng in deze door vrouwen gedomineerde afdeling.

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Curriculum Vitae

Jan Koetsenruijter was born in Fijnaart, Noord-Brabant on October 31st, 1981. He finished his high school at the Norbertuscollege in Roosendaal in 2000. After finishing his propaedeutic year in management, economics, and law (MER), he started a study in sociology at the Radboud University in Nijmegen in 2003. During his Master in 2008 he started working at the department IQ healthcare of the Radboudumc where he performed a social network analysis on networks of healthcare providers. After finishing his Master in 2009 he continued working at the department IQ healthcare as a research assistant were he participated in a range of projects, both within and outside the department. Also he was member of the statistical support group of the department. In 2012 he went to the UK to work on a research project at the University of Manchester for three months.

After coming back in 2012, he started his PhD under supervision of Prof. Michel Wensing at IQ healthcare, Radboud University Medical Center in Nijmegen, The Netherlands. The topic of his PhD contained a mix of healthcare and sociology by looking at social networks of patients with type 2 diabetes.

Since April 2016 Jan works as a researcher at the department for general practice in Aarhus, Denmark.